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Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0000e349>

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Joanna C. Macnamara BSc Hons

**Identity and acceptance of mental health problems and related
disabilities in individuals with severe and enduring mental health
problems**

**A thesis submitted in partial fulfilment of the requirements of the Open University
for the degree of Doctor of Clinical Psychology**

May 2001

SALOMONS

CANTERBURY CHRIST CHURCH UNIVERSITY COLLEGE

20,000 words

DECLARATION FOR DISSERTATION

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Date 17 / 6 / 2000

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Acknowledgements

I am very grateful to Gary Brown for his consistent supportiveness and valuable comments during the writing up of the final draft. I would also like to thank Len Rowland for his words of wisdom throughout the setting up, analysis and writing up of this research study. I would like to thank Margie Callanan for her encouragement and advice and Sue Holttum for advising me about the statistical analysis. I am grateful for the support of staff from each mental health team, who took the time to consider clients who were suitable and to refer those who were willing to participate. I would also like to thank the participants who took part in the study, without whom the research could not have taken place.

I am especially grateful for the enduring support of my family and close friends who have maintained their faith in me throughout this training.

ABSTRACT



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ABSTRACT

The research literature proposes that the concept of identity may be central to understanding responses to having severe and enduring mental health problems. Theorists hypothesise a relationship between identity and the individual's acceptance of having mental health problems mediated by societal pressures. Given the inconclusive findings from research carried out a decade ago, this study has attempted to explore whether the participants' identification as a community member or patient affected, or was affected by, their belief that they have mental health problems, need medication, need to see healthcare professionals and their awareness of disabilities. A quantitative methodology was employed to examine the main variables.

Forty five individuals living in the community with a diagnosis of schizophrenia, bipolar affective disorder or schizoaffective disorder were interviewed. Both within-group and between-group analyses were employed. The relationship between the independent variables and their relationships with socio-demographic and diagnostic factors, self-esteem and health and social functioning were explored. Measures that had been either standardised or used in previous related research were employed. The three central measures were taken from previous research studies in this area. Socio-demographic information was obtained from clinical files.

Neither beliefs about mental health problems nor awareness of disabilities were found to be associated with identity, as measured in this study. Health and social functioning and work-related variables appeared to contribute to an identification as a community member. It is suggested that defensive responses to disabilities existed to protect the individual's sense of self-worth. Furthermore, socially valued experiences prior to illness and level of ability may have contributed to the participants' identification as a community member. The clinical implications are discussed.

INDEX

	Page
Abstract	
1.0 INTRODUCTION	1
1.1 Conceptualising and defining severe and enduring mental health problems	2
1.2 The experience of living in the community for people with SEMH problems	4
1.3 Identity development within individuals living with SEMH problems	5
1.3.1 Social processes contributing to the development and maintenance of an identity within individuals with SEMH problems	6
1.3.2 Adjustment to having a SEMH problem and its impact on the individual's self-concept	8
1.3.3 An emphasis on 'patienthood' that leads to the degradation of the individual's 'personhood'	9
1.4 An identity beyond that of a 'patient' and how this can foster an adaptation to living with SEMH problems	11
1.5 Coping styles and responses to having SEMH problems	12
1.6 The potential for a relationship between identity and response to mental health problems and related disabilities	14
1.7 Justification for hypotheses and research questions in the current study	16-19
2.0 METHODOLOGY	20
2.1 Design	20
2.2 Participants	20
2.2.1 Inclusion and exclusion criteria	20
2.2.2 Characteristics of the participants	21
2.2.3 Sampling Issues	23

INDEX continued

	Page
METHODOLOGY continued	
2.2.4 Case manager ratings	24
2.3 Measures	24-28
2.4 Procedure	29
2.4.1 Ethical considerations	29
2.4.2 Recruitment procedure	29-30
2.5 Data management	30
3.0 RESULTS	31
3.1 Hypothesis 1: The individuals' belief that they have mental health problems will be associated with being more closely aligned with the psychiatric patient identity	31
3.2 Hypothesis 2: The individuals' acceptance of disabilities experienced will be associated with being more closely aligned with the psychiatric patient identity	31
3.3 Question 1: Are the individuals' beliefs that they need to take medication and see healthcare professionals associated with community member or psychiatric patient identification ?	32
3.4 Question 2: Role of socio-demographic variables and psychiatric diagnosis	33
3.4.1 Question 2 (i): Are there socio-demographic variables and diagnostic variables that are associated with the individuals' identification as a 'community member' or as a 'psychiatric patient' ?	33
3.4.2 Participants grouped according to alignment with identity categories : day-time activities	34
3.4.3 Question 2 (ii) (1): Are there socio-demographic variables and diagnostic variables that are associated with the individuals' belief that they have mental health problems ?	35

INDEX continued

	Page
RESULTS continued	
3.4.4 Question 2 (ii) (2): Are there socio-demographic variables and diagnostic variables that are associated with the individuals' belief that they need to take medication ?	37
3.4.5 Question 2 (ii) (3): Are there socio-demographic variables and diagnostic variables that are associated with the individuals' belief that they need to see healthcare professionals ?	38
3.4.6 Question 2 (iii): Are there socio-demographic variables and diagnostic variables that are associated with the individuals' view of their disabilities experienced?	40
3.5 Question 3: Role of health and social functioning	41
3.5.1 Question 3 (i): Is level of health and social functioning associated with the individuals' identification as a 'community member' or as a 'psychiatric patient'?	41
3.5.2 Question 3 (ii) (1): Is level of health and social functioning associated with the individuals' belief that they have mental health problems ?	41
3.5.3 Question 3 (ii) (2): Is level of health and social functioning associated with the individuals' belief that they need to take medication ?	41
3.5.4 Question 3 (ii) (3): Is level of health and social functioning associated with the individuals' belief that they need to see healthcare professionals ?	41
3.5.5 Question 3 (iii): Is level of health and social functioning associated with the individuals' view of their disabilities experienced ?	43

INDEX continued

	Page
RESULTS continued	
3.6 Question 4: Role of self-esteem	43
3.6.1 Question 4 (i): Is self-esteem associated with the individuals' identification as a 'community member' or as a 'psychiatric patient'?	43
3.6.2 Question 4 (ii)(1): Is self-esteem associated with the individuals' belief that they have mental health problems?	44
3.6.3 Question 4 (ii) (2): Is self-esteem associated with the individuals' belief that they need to take medication ?	44
3.6.4 Question 4 (ii) (3): Is self-esteem associated with the individuals' belief that they need to see healthcare professionals ?	44
3.6.5 Question 4 (iii): Is self-esteem associated with the individuals' view of their disabilities experienced ?	44
3.7 Other results of interest	44
4.0 DISCUSSION	46
4.1.1 Summary of results	46
4.1.2 The participants in the current study in comparison with Taylor and Perkins' study	47
4.2 The participants' identification	47
4.3 The participants' belief that they have mental health problems, need to take medication and need to see healthcare professionals	48 - 49
4.4 The participants' view of their disabilities	49 - 50
4.5.1 The clinical relevance of the findings	51- 53
4.5.2 The implications of the findings for clinical practice	53 - 55

INDEX continued

	Page
DISCUSSION continued	
4.6.1 Analytic and statistical issues	55 - 56
4.6.2 Discussion of method	56 - 58
4.6.3 Issues concerning measures used	58 - 59
4.6.4 Issues raised in the research interview	59 - 60
4.7 Development of theories and future research	61 - 62
4.8 Conclusions	62
REFERENCES	63 - 74
Appendices	

LIST OF TABLES

	Page
Table 1: Characteristics of the participants	21
Table 2: Additional demographic characteristics of the participants	21
Table 3: Participants' level of health and social functioning	22
Table 4: The participants' identity and belief that they have mental health problems	31
Table 5: Relationship between the participants' degree of identification with identity categories and acceptance of disabilities	31
Table 6: The participants' identity and their beliefs that they need to take medication and need to see healthcare professionals	32
Table 7: Socio-demographic and diagnostic characteristics: participants grouped according to alignment with identity categories	33
Table 8: Identity groups and participation in community and psychiatric service-related activities	35
Table 9: Socio-demographic and diagnostic characteristics: participants grouped according to their belief that they have mental health problems	36
Table 10: Socio-demographic and diagnostic characteristics: participants grouped according to the belief that they need to take medication	37
Table 11: Socio-demographic and diagnostic characteristics: participants grouped according to their belief that they need to see healthcare professionals	38
Table 12: Socio-demographic and diagnostic characteristics: participants' view of their disabilities	40
Table 13: Participants' health and social functioning and the main variables	42
Table 14: Participants' self-esteem and the main variables	43
Table 15: Other results of interest	45

1.0 INTRODUCTION

Service models and national standards for the treatment of people with severe and enduring mental health (SEMH) problems recently came under review (National Service Framework for Mental Health (NSFMH),1999). The review focused on the potential for systematic, sustainable changes for promoting mental health and treating mental illness. This review emphasised the importance of addressing social exclusion and discrimination against people with SEMH problems that impact on an individual's self worth, integration into communities and ultimately the adaptation to living with SEMH problems.

With specific reference to difficulties in adapting to having a SEMH problem, this may stem from a discrepancy between how individuals see themselves and the meaning they attribute to having had a mental illness, to the occurrence of residual symptoms and to an ongoing risk of relapse (Estroff, 1989; Perkins & Dilks, 1992). The process of accepting having mental health problems may involve characteristics which they value within themselves being placed under threat. Difficulties in managing these incompatibilities could lead to the mental health problem being denied (De Leon, Saiz-Ruiz, Chinchilla & Morales, 1987; Shepherd, 1984). Alternatively, acceptance of having a mental health problem and its integration into an individual's self could either take the form of the mental health problem overriding other aspects of his or her identity, or could be viewed as one part of a complex sense of self (Gara, Rosenberg and Cohen,1987).

The nature of the relationship between an individual's identity and the way he or she responds to having a SEMH problem has received limited attention in the research literature. Given the need for further exploration, this study aims to review a sample of individuals with SEMH problems living in the community and the processes impacting on their identity development. The possibility of a relationship between the identity individuals adopt and how they respond to having a SEMH problem will also be considered. Given the complexity of the nature of what it means to live with SEMH

problems, it is important first to establish the key concepts that can inform a definition.

1.1 Conceptualising and defining severe and enduring mental health problems

The Mental Health Foundation (1994) estimates that 300,000 people in England and Wales have a severe mental illness. The Office of Population Censuses and Surveys estimates that in Great Britain at any one time, one person in 250 will have a functional psychosis, defined as schizophrenia, schizoaffective and bipolar affective disorder (Meltzer, Gill, Petticrew & Hinds, 1995).

As government policy has prioritised aiding people with SEMH problems (DoH, 1990, 1994a, 1994b), so defining who this refers to has become important. However there is no widely agreed consensus on a definition (DoH, 1997a; Thornicroft & Tansella, 1999). Definitions of people with SEMH problems which focus on their duration and length of service contact have led to the consideration of the subgroups ‘old long-stay’, ‘new long-stay’ and ‘new long term’ clients (Wing & Morris, 1981). The ‘old long-stay’ clients were admitted to hospital in the institutional era and often lived there most of their lives. This group includes individuals who, due to continuing to manifest acute psychiatric symptoms and behavioural problems, continue to require hospitalisation and tended to have resettled in the community with a high level of support. Such individuals either no longer have acute symptoms or have symptomatology which does not interfere with their daily life. The second group, the ‘new long-stay’ clients, became unwell in the post-institutional era and have moved continuously between acute hospital wards and supported community accommodation as ‘revolving door’ clients. ‘New long-stay’ clients tend to manifest significant behavioural problems, active symptomatology or a fluctuating mental state. This group is often not chronically institutionalised and hold normal ambitions. The third group, ‘new long term’ clients are distinguished from the other groups through not staying in hospital for long periods of time and making frequent use of a variety of community-based services over a prolonged time.

Other approaches to defining SEMH problems have focused on at least one of the following as present: at least a two year contact with psychiatric services; prescription of psychotropic medication given by injection; three or more inpatient admissions or day-patient episodes in the last two years (McLean & Liebowitz, 1989). However, duration of problems can be more helpful to consider than duration of service contact alone. This relates to duration of service contact excluding those who are not in contact with services for long enough to be considered 'long-term' despite their problems and disabilities being of an enduring nature.

The focus on diagnosis in defining people with SEMH problems is insufficient, through not being predictive of the course and outcome of difficulties, such as disability support needs and the enduring nature of the illness (Perkins & Repper, 1996,1998). An improved definition is based on two key areas, that of : diagnoses of schizophrenia, schizo-affective, bipolar disorders, major depression and delusional disorders; secondly, the consideration of disabilities seriously impairing functioning of role performance in at least one of the following areas: occupation, family responsibilities or accommodation (Goldman, 1981).

In terms of the experience of living with SEMH problems defined as psychoses, Bachrach (1988) proposed that chronicity, problem definition, disability and complexity may be central to the individual's survival in the community. To further develop our understanding of the meaning of having a serious mental illness, Kleinman (1988) distinguishes between the concepts of 'illness' and 'disease'. Disease refers to mental health problems being viewed as a disease of the central nervous system characterised by brain abnormalities, whereas illness relates to how the individual, their relatives and social network respond to the symptoms and associated disabilities. The concept of illness relates to the meaning of going through the ordeal of hospital admissions, becoming a 'mental patient' and the impact of these on the individual's sense of self. Other concepts important in understanding the processes involved in the experience of a chronic mental illness include 'disability'

and 'handicap' (Ramon, 1991). Disability is defined as impaired performance of an activity that fails to meet the demands of a situation. A handicap is defined as a disadvantage for an individual, resulting from a disability, which limits the role expected of him or her.

The impact of disabilities and handicaps on the individual's day-to-day life is central to understanding the experience of living with SEMH problems. This can include a sense of failure and a loss of the person they expected to be. This is compounded by the view taken of people important to them, which can include a sense of the individual's failure to live up to their expectations. Social disabilities are a function of the symptoms of the individual's mental health problems, the ways in which these are responded to and the social disadvantages they experience (Perkins & Repper, 1996). Thus, the way in which individuals respond to and cope with the social disadvantages can have at least as great a bearing as their symptoms on their daily life. To explore this further, it is helpful to gain an overview of the issues impacting on an individual's adjustment to experiencing SEMH problems.

1.2 The experience of living in the community for people with SEMH problems

It has been emphasised how incongruous it is to define people as 'living in the community' when a large proportion of individuals with SEMH problems inhabit segregated housing outside hospital and have no community network (Perkins & Repper, 1996). Over a decade ago, Lewis, Shadish and Lurigio (1989) anticipated a number of implications of the enforced inclusion of individuals with SEMH problems into society suggesting that they are,

'neither outside society in the world of exclusion, nor are they full citizens' (p.174).

Surveys in England and Wales of the public's attitude towards community mental health facilities have suggested opposition increased between 1992 and 1997, with the main concern being around safety, violence (Dunn, 1999; DoH, 1997b) and falling property prices (Repper, Sayce & Strong, 1997). The public's attitude continues to be fuelled by the media portrayal of mental illness, with the link between

madness, dangerousness and disruption having become strong in the minds of the public (HEA,1997). This has resulted in damaging this group's reputation and has overshadowed community care attainments.

In considering community living for people with SEMH problems, the Mental Health Foundation's (1994) enquiry stated that,

‘Having a mental illness, even a severe one, does not change the basic human search for a full and fulfilling life. Nor does it alter the fundamental requirements on which such a search is necessarily grounded – an appropriate place to live, an adequate income, a meaningful social life, employment or other satisfactory day activity and help and support when in need’ (p.17).

The emphasis on shortcomings in the meeting of basic human needs for a meaningful life relates to aspects of community living for people with SEMH problems which could in turn impact on each individual's identity.

1.3 Identity development within individuals living with SEMH problems

Individuals entering psychiatric healthcare can acquire the label ‘psychotic’ whilst having to adapt to a range of experiences, including a profound cognitive and emotional upheaval, altered perceptions, cognitive confusion and attentional deficits (Perkins & Dilks, 1992). These experiences coincide with the alteration of the individual's perception of self and in terms of how they are known by others. Indeed, the enduring nature of labels attached to a diagnosis when symptomology is no longer apparent, indicates how mental illness represents more than a collection of symptoms.

As Estroff (1989) emphasised, the sense of self as an enduring entity that preceded the illness and that is more than a diagnosis or illness, can be overlooked by people they encounter. Equally, Herzlich and Pierret (1987) state that,

‘By enforcing inactivity, illness thus prevents individuals from ‘playing their role’, marginalises them

and can even provoke a loss of identity.’ (p.178).

The means by which identity can develop for individuals with SEMH problems requires an exploration of the social processes impacting on identity development.

1.3.1 Social processes contributing to the development and maintenance of an identity within individuals with SEMH problems

Theories of identity range from the self viewed in terms of the individual’s innate traits to being viewed as a social product (Wetherall & Potter, 1989). Social learning theory proposes that the processes by which individuals acquire an identity are affected by both internal and external factors. Emphasis is placed on cognitive locus of control and the reinforcement of action (Mischel, 1971; Rotter, 1982). Bandura (1977) highlighted the role of vicarious learning and its interaction with factors ranging from attention to information through to attitude and beliefs. Thus, learning is regarded as occurring through symbolic and cognitive processes, with cognitions determined by past experiences.

The interactional model regards self-concept as synonymous with the term identity and as a ‘multi-faceted and dynamic entity’ (Oyserman & Markus, 1992, p.6). The self-concept is viewed as influenced by a variety of socio-cultural factors and includes social and role identities together with individual attributes. The self-concept is proposed as mediating an individual’s interpersonal and intrapsychic functioning. This model proposes that the ‘private self’ is formed and maintained within social interactions (Tedeschi, 1986). This relates to the view taken by symbolic interaction theory about the development of the self whereby the basis of an individual’s identity develops within society through meaningful discourse between individuals (Mead, 1934). Individuals observe the effects of their actions reflected back at them, through responses and attitudes communicated by others. Goffman (1961) described how the ‘mental patient’ role adheres to individuals defined as mentally ill through others’ expectations of them. These expectations become part of a ‘moral career’ from which it is hard to escape once individuals are stripped of their old identity and a new identity takes its place. Essential

to this process, Harre (1979) described how initial impressions that group members have about an individual's attributes govern their expectations of and responses to that person.

Labelling theory describes how patient roles are negotiated and upheld (Scheff, 1966). The psychiatric illness label is viewed as causing the individual to conform to expectations of the role. However, evidence from the literature indicates that the reputed negative effects of being labelled a mental patient are not as clear-cut as labelling theory predicts (Hayward and Bright, 1997). Link, Cullen, Struening, Shrout and Dohrenwend (1989) proposed a 'modified labelling theory' of mental illness, in which stigma does not play a key causal role. They suggested that stigma decreases self-esteem and social interaction, which results in maladaptive styles of coping. Thus, these processes are further compounded through the individual's subsequent behaviour being regarded as fulfilling expectations related to a negatively valued role. In a further criticism of labelling theory, individuals are seen as playing an active part in constructing new roles, so that these may never be wholly determined by perceptions held by the general public. It has been argued that if the public played such a significant role in creating mental illness through their reactions to primary deviance, stereotypes of mental illness would be more consistent with the range of behaviours displayed. This runs counter to the available evidence (Jones & Cochrane, 1981).

For an individual with SEMH problems when his or her behaviour and experiences conflict with dominant social values of ruling groups, this can result in experiences of shame (Lewis, 1992). Breaching such values is viewed as leading the individual to see him or herself as inferior. This can render the individual vulnerable to experiencing a sense of defenselessness against a perception of others' superiority, which then serves to create a sense of shame (Gilbert, 1998). This in its turn can result in the individual feeling threatened by interacting with others. Fear of rejection can limit the individual's development of support networks (Link et al., 1989). Since it is within social relations that the self is fostered, restricted social contact can limit the development of the self-concept.

The impact of social experiences on the individual's perception and expectations of the self interacts with symptoms experienced. This challenges his or her sense of self. An understanding of how these processes impact on an individual may be central to appreciating the nature of an adjustment to living with a SEMH problem.

1.3.2 Adjustment to having a SEMH problem and its impact on the individual's self-concept

In terms of the implications for rehabilitation, the individual's adjustment to a SEMH problem has been recognised as contributing to both social impairment and successful treatment (Perkins & Repper, 1996). Whilst it had been found that increased acceptance of having a mental health problem has a negative impact on well-being, equally it has been shown that acceptance is a better indicator of prognosis than denial (Warner, Taylor, Powers & Hyman, 1989). Thus, acceptance of illness may be an important treatment goal so long as effects on the self-concept are also addressed. It has been argued that individuals are as impaired by their definition of themselves as they are by their illness (Lally, 1989). In relation to the origin of the individual's perception of what it means to have a SEMH problem, Porter (1987) stated how individuals,

'complain that 'alienness' is a false identity thrust upon them, or indeed a non-identity, a sense of being rendered a non-person' (p.25).

The narrative of loss has tended to be associated with traditional psychiatric accounts of schizophrenia, with the pre-illness individual described as abandoned due to the disorder and losses resulting from disabilities. Thus, an admission and long hospitalisations can result in acceptance of oneself as mentally ill and a resigning of oneself to never again being 'normal' (Lally, 1989).

Relevant to the impact of hospital admissions, in a study of individuals with SEMH problems who had experienced long hospitalisations it was found that individuals believed that they were unable to change their environment and that what happened to them was determined by outside agencies (Waismann, 1988). The perception of external causality was evident at the time of their first admission

(Waismann,1988). The perception of external causality was evident at the time of their first admission and continuous contact with services exacerbated the degree of the externality of their locus of control for events. This has implications for services provision for an individual's range of needs which can serve to reinforce his or her belief in their lack of control over events.

The adoption of a role as a patient has been argued as dependent on the existence of the number of alternative competent roles and obligations associated with these roles (Thoits, 1986; Marcus, Seeman & Telesky,1983). This could partially explain how some individuals prevent the experience of their illness from influencing the primary definition of themselves. Following this, Robey (1994) proposed that the promotion of membership of groups beyond the patient community may be more helpful than aiming to reduce identification with a patient role.

The individual's unique experiences, beliefs and knowledge can be obscured by the label of mental illness. To counteract this, the personhood of the individual with a SEMH problem needs to be emphasised, through a distinction being drawn between that of the 'person' and the 'illness'.

1.3.3 The emphasis on 'patienthood' that leads to the degradation of the individual's 'personhood'

Research has located positive change as dependent on emphasising the individual's 'personhood' rather than 'patienthood' within individuals with SEMH problems (Barham & Hayward, 1995). Progress may involve integrating the individual's sense of self that existed before the illness with changes that took place as a result of what was endured during the illness.

Experiences of marginalisation shared by people with SEMH problems have been regarded as stemming from a medical, as opposed to a psychosocial, view of mental health problems which

encourages the adoption of an identity of patienthood (Augostinos, 1986). Estroff (1981) explored the creation and maintenance of a 'mental patient' identity and the processes assisting in the amplification and maintenance of 'differentness' and hypothesised that the limited social participation outside the patient community has as powerful an effect as that of stigma.

To counteract the detrimental effects of marginalisation, an emphasis of the individual's personhood needs to occur alongside enhancing his or her experienced quality of life and addressing the public's perception of people with SEMH problems. This can involve using culturally normative means to establish and maintain socially valued roles, experiences and social images for individuals, without forcing expectations on those unable to manage them (Wolfensberger, 1972, 1983). These principles from 'normalisation' and 'social role valorisation' (SRV) can then inform approaches to care and each individual's rehabilitation into the community.

Thompson (1989) found that the meanings that individuals attributed to their mental health problems corresponded to the perceived supportiveness of social networks that enhanced their recovery, rather than that of hospital experiences. Individuals who expected a negative outcome were, however, more socially isolated and dependent on recovery enhanced through a professional network. This would support the importance of encouraging membership of wider social groups and participation in community as well as service-related activities, alongside addressing the public's inherited discomfort.

In summary, in order to overcome potential determinants of marginalisation, enquiries into experiences of life in the community for people with SEMH problems, such as that carried out by the Mental Health Foundation (1994) and the MIND enquiry (Dunn, 1999), are needed. The reconstruction of an identity for individuals within this group involves accepting that as a 'person with mental health problems', individuals may not wish their lives to be based around their mental illness.

1.4 An identity beyond that of a ‘patient’ and how this can foster an adaptation to living with SEMH problems

Where a tendency has been found amongst people with SEMH problems to distance themselves from their diagnosis, this has led to the shift from a permanence of ‘mental patienthood’ to the integration of more negotiable identities (Barham & Hayward, 1995). In addition, Davidson and Strauss (1992) described an independent and enduring sense of self as serving as a refuge from the illness. This can progress to a realistic appraisal of the self taking place by building on strengths and compensating for areas of dysfunction. The individual’s active collaboration in treatment and rehabilitation is viewed as contributing to the facilitation of recovery, with improved self efficacy in one area potentially generalising to other areas of functioning (Davidson & Strauss, 1992, 1995). This may include the individual’s involvement in developing coping strategies (Carr, 1988), greater symptom control (Breier & Strauss, 1983) and relapse prevention (Birchwood, 1996; Perry, Tarrier, Morris, McCarthy & Limb, 1999). Thus, the individual’s active involvement in treatment can overcome the sense of hopelessness and passivity that promotes the patient role and limits the adoption of alternative functional roles.

Perkins (1999) highlighted the facilitation of ‘recovery’, involving the redefinition and redevelopment of life to acquire new meaning and purpose beyond the limits of disability. Factors influencing the enhancement of self-esteem and identity include adequate housing with the aim of working towards, where appropriate, the individual having a place of their own, gaining qualifications, employment, enhancing financial resources, developing and maintaining relationships and participating in leisure activities (Lehman, Ward & Linn, 1982; Perkins & Repper, 1996; Rowland and Perkins, 1988).

A variety of social circumstances and opportunities may contribute to both an identity beyond that of a ‘patient’ and the adaptation to living with SEMH problems. Having begun examining the contribution of social factors on illness-related disabilities and handicaps, ways that individuals respond

to living with SEMH problems shall now be considered.

1.5 Coping styles and responses to having SEMH problems

Responses to having a SEMH problem have been viewed as just as important in determining disablement as the illness symptoms themselves (Perkins and Repper, 1996; Wing & Morris, 1981). Assumptions about the irrationality of opinions held by individual with SEMH problems can lead to a lack of curiosity about what is behind the denial of a mental health problem. When an individual does not agree with the healthcare professional's opinion about the 'illness' and need for treatment, this is often viewed as symptomatic of their illness (Pilgrim & Rogers, 1999). An understanding of mental health problems may be independent from endorsing recommended treatment, with for example treatment side-effects influencing acceptance of treatment offered.

As a response, denial is conceptualised as a defence mechanism protecting individuals from the pain of his or her situation. Advocates of this theory often subscribe to a psychodynamic orientation, regarding denial as having an ego-adaptive function (Vaillant 1971). Denial of a diagnosis could also be due to an individual's wish to be recognised in terms of his or her persisting healthy self who, despite a struggle, is determined to survive the illness and the associated stigma. As Pilgrim and Rogers (1999) emphasise, to 'choose' between voluntarily accepting or being forced to accept treatment may equate, in the individual's mind, to being forced to accept an identity as that of a 'psychiatric patient'.

Shepherd (1984) identified reactions to having SEMH problems as, alternatively, denial of mental health problems associated with a tendency to reject help, or the exaggeration of mental health problems linked to a tendency to become dependent on services, lose confidence and avoid challenges. Adopting a 'sick role', which Shepherd related to exaggeration, has been viewed as, 'a passive acceptance of the threat, a giving up and allowing others to take over control' (Taylor, 1989, p.8).

Taylor (1989) likened the ‘sealing-over’ and ‘integrative’ styles of coping described by McGlashan (1987) to those of denial and exaggeration. In a study of individual hospital residents’ recovery from schizophrenia, individuals who adopted an integrative style of coping tended to search for meaning in their illness (McGlashan, 1987). These individuals tended to accept responsibility for their illness, integrate it with previous experiences and gain help from others and were accepting of their patient status. Individuals with a sealing-over style were found to minimise the impact of their illness, to decline help and to reject the ‘mental patient’ label. Taylor and Perkins (1991) suggested that the integrators could include individuals accepting their mental health problems and associated disabilities, as well as those exaggerating them. It could also be argued that the two styles, integrating and sealing over, may not be mutually exclusive, but may be involved at different stages of recovery.

Factors impacting on the experience of the patient role could be conceptualised as revolving around the instilling and disintegration of hope (Nunn, 1996). Perceived mastery through personal agency, environmental flexibility and illness responsiveness are important through being pivotal to the establishment of hope. Furthermore, a sense of purpose and the ability to make sense of one’s experience are each viewed as potentially encouraging hope (Fitzgerald, 1979). Indeed, the maintenance of hope may be essential to an integrative style of coping with mental health problems.

In summary, for an individual to take a ‘non-psychiatric’ view of him or herself and to make a similar requirement of others in their dealings with him or her, may not imply denial of mental health problems. Instead the individual may not wish to draw attention to this area more than is necessary. Barham and Hayward (1995) considered it invaluable that individuals are supported in having a life, alongside the illness, involving themselves in community as well as service-related activities. The focus on what individuals with mental health problems can do, or can be enabled to do, to help themselves is critical. Experiencing life events common to most community members may allow the establishment of similarities with others to strengthen the part of themselves that continues to be healthy and

functioning despite a chronic mental health problem (Estroff, 1989). The literature discussed suggests that a relationship could exist between identity adopted and response to mental health problems. The evidence within the research literature shall now be reviewed.

1.6 The potential for a relationship between identity and response to mental health problems and related disabilities

Breakwell (1986) proposed that an individual's response to identity-threatening experiences can be conceptualised as coping strategies adopted in order to limit damage to self-esteem. Breakwell postulated that a need for continuity across time and situation, uniqueness or distinctiveness and a feeling of personal worth related to coping strategies adopted within identity change. Thompson (1988) hypothesised that having a mental illness could jeopardise each of these processes, which could lead to the adoption of denial and exaggeration of problems as coping responses.

With the high value placed on autonomy in western culture, the loss of roles and a struggle to perform tasks, this may confirm a belief that previous identities cannot be reaffirmed (Price, Sloman, Gardner, Gilbert & Rohde, 1994). Such beliefs can encourage the adoption of a patient identity as a defensive manoeuvre (Birchwood, Mason, MacMillan & Healey, 1993). Thompson (1988) argued that adopting a patient identity may be related to the exaggeration of illness. This could allow an individual to sustain self-esteem if his or her acceptance of the role gains positive feedback. Equally, denial of the illness could serve to maintain self-esteem, continuity and distinctiveness through negating the individual's need to modify their identity.

An accumulation of experiences, such as symptoms, receiving a stigmatised diagnosis, disabilities and living on benefits, can have a bearing on the individual's self-concept. Lally (1989) described how 'engulfment' into a patient identity can take place, whereby individuals can experience the reorganisation of their identity so that it is increasingly constructed around the devalued role of the

psychotic patient.

Previous research on the relationship between self-concept and responses to having a SEMH problem has proven inconclusive. Thompson (1988) found that amongst individuals with a major mental health problem who experienced long hospitalisations, those who viewed themselves as 'community residents' were less likely to find services helpful or to use medication. Thompson also found that those who viewed themselves as 'mental patients' were more dependent on services. These findings supported Shepherd's (1984) proposal that an individual's identity is related to behaviour occurring as a reaction to having mental health problems. Service usage was reviewed in Bender and Pilling's (1985) exploratory study, in their finding that the discrepancy between their view of self and view of other clients was predictive of under-attendance at a day centre. Thompson's findings were, however, not supported by Taylor and Perkins (1991) who found that amongst clients with major mental health problems, identity as a community member or a patient was not predictive of denial or exaggeration of mental health problems.

The contradictory findings relating to the nature of the relationship between identity and response to having severe mental health problems highlights the need for further research. A better understanding of the relationship between these variables could inform developments within rehabilitation and treatment. The key themes emerging from the literature that inform the present study shall now be outlined.

1.7 Justification for hypotheses and research questions in the current study

The bio-social, stress-vulnerability model underlying psychiatric rehabilitation aims to identify and minimise causes of social disablement. These disabilities are seen as resulting from an interaction between personal reactions to psychiatric impairment and social disadvantages (Perkins & Dilks, 1992; Wing & Morris, 1981). As a consequence, the promotion and development of social networks and valued social roles within the community are central to rehabilitation and community care services. Rehabilitation aims to enable the individual with SEMH problems to identify him or herself with a wider community, whilst acknowledging his or her specific problems. The means by which this may be achieved needs to stem from an appreciation of the individual's experiences in adjusting to having SEMH problems.

As the research on identity and response to having SEMH problems discussed in the introduction has indicated, existing studies were carried out over a decade ago and have yielded inconclusive results. Since the nature of psychiatric services has changed significantly in that time, the relevance of many of the reported findings is now questionable. There is, therefore, a need for further research on the key variables, identity and stance taken in response to SEMH problems.

In order to examine how identity is affected by the experience of having SEMH problems, the present study will draw on a study carried out by Taylor (1989). As was done in that study, the degree to which each individual's self-identity resembles their perception of what being a 'psychiatric patient' entails as compared to what being a 'community member' entails, will be examined. For the sake of brevity, this dimension, relating to where a person falls on the continuum between identifying themselves as a community member and a psychiatric patient, will be referred to as 'identification'. The second variable of interest is the stance an individual takes in response to the experience of having SEMH problems. As the literature indicates, the nature of the stance an individual takes in response to having a SEMH problem can incorporate a variety of components, including recognition of the

mental health problem and the consequent needs for medication and seeing healthcare professionals and acknowledgement of any disabilities that develop (De Leon et al., 1987; Pilgrim & Rogers, 1999). Accordingly, the current study will examine participants' stance taken in relation to each of these components. This exploratory study has the potential to contribute to informing approaches that seek to improve the quality of life of individuals with SEMH problems, who are vulnerable to the effects of social exclusion, discrimination and stigma within everyday interactions with others.

Hypothesis 1

The individuals' belief that they have mental health problems will be associated with being more closely aligned with the psychiatric patient identity.

The first hypothesis examines whether a relationship exists between denial or acceptance of having SEMH problems and identification. The aim is to explore whether individuals who see themselves as most closely identified as a patient more readily accept having a stigmatised SEMH problem and, conversely, whether individuals who see themselves as most closely identified as a community member have greater difficulty acknowledging having SEMH problems.

Hypothesis 2

The individuals' acceptance of disabilities experienced will be associated with being more closely aligned with the psychiatric patient identity.

Based on the previous research (Taylor, 1989; Taylor & Perkins, 1991), the second hypothesis relates to the relationship between identification and stance taken in response to disabilities experienced. This hypothesis relates to whether individuals who are most closely identified with the patient identity accept having disabilities and, conversely, whether individuals who identify themselves most closely as a community member do not accept having stigmatised disabilities.

Question 1: Are the individuals' beliefs that they need to take medication and see healthcare professionals associated with community member or psychiatric patient identification ?

This pertains to the relationship between identification and stance taken in relation to need for medication and healthcare professional involvement. The question seeks to determine whether individuals identifying themselves most closely as a community member would deny need for medication and healthcare involvement and whether individuals identifying most closely as a patient would be more accepting of these needs.

Question 2: Role of socio-demographic variables and psychiatric diagnosis.

(i) Are there socio-demographic variables and diagnostic variables that are associated with the individuals' identification as a 'community member' and as a 'psychiatric patient' ?

(ii) Are there socio-demographic variables and diagnostic variables that are associated with the individuals' belief that they (1) have mental health problems, (2) need to take medication and (3) need to see healthcare professionals?

(iii) Are there socio-demographic variables and diagnostic variables that are associated with the individuals' view of their disabilities experienced?

Continuing to expand on exploring identification, the first question relates to socio-demographic variables cited in the literature as potential determinants of an engagement in the role of a patient or identification as a member of the general community. The relationship between these variables and stance taken, as referred to in the latter two questions, would also contribute to an understanding of the experience of living with SEMH problems. The socio-demographic variables of interest include the acquisition of qualifications and current and previous employment (Lehman et al., 1982; Perkins & Dilks, 1992; Rowland & Perkins, 1988), the existence of significant relationships with others (Lehman et al., 1982; Perkins & Repper, 1996) as well as length of contact with psychiatric services and time spent hospitalised (Thompson, 1988, 1989). Further factors include receiving a diagnosis (Estroff, 1989; Lally, 1989), living in staff-supported accommodation (Perkins & Repper, 1996) and

participation in service-related as opposed to community activities (Barham & Hayward, 1995; Estroff, 1989).

Question 3: Role of health and social functioning.

Is level of health and social functioning associated with the individuals’:

(i) identification as a ‘community member’ or as a ‘psychiatric patient’ ?

(ii) belief that they (1) have mental health problems, (2) need to take medication and (3) need to see healthcare professionals?

(iii) view of their disabilities experienced ?

The above questions relate to an individual’s functioning, in terms of symptomatology (Perkins & Repper, 1996), level of cognitive functioning (Perkins and Dilks, 1992), behavioural problems and social skills (Perkins and Repper, 1996), which are cited in the literature as potentially contributing to disabilities experienced. The relationships between each of these variables and identification and stance taken would enhance an understanding of responses to actual disabilities experienced.

Question 4: Role of self-esteem.

Is self-esteem associated with the individuals’:

(i) identification as a ‘community member’ or as a ‘psychiatric patient’?

(ii) belief that they (1) have mental health problems, (2) need to take medication and (3) need to see healthcare professionals ?

(iii) view of their disabilities experienced ?

The literature cited suggests that identity adopted and stance taken in response to having a SEMH problem may be based on maintenance of self-esteem (Breakwell, 1986; Lally, 1989), which may play a central role within the adjustment process.

2.0 METHODOLOGY

2.1 Design

The study employed a cross-sectional correlational design.

2.2 Participants

2.2.1 Inclusion and exclusion criteria

Participants met the following selection criteria:

Inclusion criteria

1. A current diagnosis of either schizophrenia, schizoaffective disorder or bipolar affective disorder (ICD 10: categories F20, F25, F31)
2. Residing in community settings, which could include any of the following: living with staff support varying from 24 hours to 8 hours daily, living independently, living with parents, with family or with a partner.

Exclusion criteria

1. The existence of organic aetiology established through report of a psychological assessment in their records.
2. The presence of learning difficulties established through psychometric assessment or where individuals exhibited an inability to comprehend the nature of the study so preventing informed consent from being achievable.
3. Staff judgement of an inability to concentrate for a 30 minute interview.
4. A dual diagnosis involving substance or alcohol abuse.

2.2.2 Characteristics of the participants

Forty five participants with SEMH problems were recruited from the health care Trusts.

Table 1: Characteristics of the participants

Variables	Schizophrenia N= 30		Bipolar affective disorder N= 11		Schizoaffective disorder N= 4	
	Median	Range	Median	Range	Median	Range
Age	47	28 - 63	45	36 - 65	39	33 - 53
Length of contact with psychiatric services (years)	21.5	10 - 36	20	10 - 43	14.5	10 - 35
Years spent in hospital	3.54	0.48 - 12.58	2.08	0.42 - 23.42	2.15	0.42 - 14.58
Years worked in a job	5	0 - 27	10.4	0 - 29	4.65	1 - 22

As Table 1 indicates, the participants were aged between 28 to 65 years of age and had at least a ten year history of mental health problems. As can be seen from Table 2, most participants were male, European and had a diagnosis of schizophrenia.

Table 2: Additional demographic characteristics of the participants

	Schizophrenia N (%)	Bipolar Affective Disorder N (%)	Schizoaffective disorder N (%)
Gender: Male Female	23 (77) 7 (23)	6 (55) 5 (45)	2 (50) 2 (50)
Ethnicity: European African Afro-Caribbean Asian	21 (70) 1 (3.5) 7 (23) 1 (3.5)	11(100) 0 (0) 0 (0) 0 (0)	4 (100) 0 (0) 0 (0) 0 (0)
Accommodation: Independent living Day-time supported 24-hour supported Living with family	7 (23) 9 (30) 13 (43) 1 (4)	5 (45) 2 (18) 3 (27) 1 (10)	3 (75) 0 (0) 1 (25) 0 (0)
Relationship status: In significant relationship Not in significant relationship	9 (30) 21 (70)	2 (18) 9 (82)	2 (50) 2 (50)
Employment status: In employment (Voluntary or paid) Not in employment	7 (23) 23 (77)	4 (36) 7 (64)	1 (25) 3 (75)

The majority of participants (36 out of 45) were European, thus this sample under-represented people from other cultural backgrounds. The data on the nature of each individual’s accommodation, relationships and employment provide an indication of the participants’ level of functioning and the impact of their problems on their lives.

On the basis of the fourth and most recent version of the Health of the Nation Outcome Scales (HoNOS) (Wing, Curtis & Beevor, 1999), the participants’ overall level of functioning as defined by their total scores, ranged from 2 (minor to mild problems) to 24 (moderate problems).

Table 3: Participants’ level of health and social functioning

	Schizophrenia N = 30		Bipolar affective disorder N = 11		Schizoaffective disorder N = 4	
Name of scale (Maximum score)	Median	Range	Median	Range	Median	Range
HoNOS*Total scale (48)	7.5	2 - 22	6	2 - 24	11.5	9 - 20
HoNOS subscales:						
Behaviour ¹ (12)	1	0 - 4	1	0 - 4	1.5	1- 3
Functional ² (8)	1	0 - 6	2	0 - 6	1	0 - 2
Symptoms ³ (12)	3	0 - 8	3	1 - 9	4	4 - 9
Social ⁴ (16)	3	0 - 7	2	0 - 9	5.5	2 - 7

*Health of the Nation Outcome Scale

¹ Behaviour subscale - Problems from overactive, aggressive, disruptive or agitated behaviour
Non-accidental self-injury
Problem-drinking or drug-taking

² Functional subscale - Problems involving memory, orientation, understanding
Physical illness or disability problems

³ Symptoms subscale - Problems associated with hallucinations and delusions
Depressed mood
Other mental and behavioural problems

⁴ Social subscale - Problems with inability to make supportive relationships
Problems with activities of daily living
Problems with living conditions
Problems with occupation and activities

It has been suggested that the HoNOS is not a good measure of SEMH problems for individuals who are not presently experiencing an acute episode of illness and, thus, most people receiving support

from psychiatric services obtain low to intermediate total scores (Adams, Palmer, O'Brien & Crook, 2000; Trauer, 1999).

2.2.3 Sampling Issues

Power analysis calculations were carried out to determine the sample size required to detect the estimated expected effect (Cohen, 1988). To determine sample size, a comparable study was reviewed from which the expected effect size was established. Since there was only one study to base the calculation on and the variables from the source study were not exactly the same as those in the current study, an exact stable estimate of power was not obtainable. The calculation of effect size revealed that where the level of power was set at 0.8, for a variable combination involving the 'Recognition of Problems' measure, for a within-subjects and between-groups analysis over 1000 participants would be required to detect an expected effect size of 0.024. However, for another variable combination where the level of power was set at 0.8, for a within-subjects analysis 14 participants would be required and for the between-groups analysis 25 participants would be needed in each group to detect an expected effect size of 0.88 or greater. In the time available it was possible to interview 45 participants. However, in each between-group analysis there was less than 25 participants in at least one of the groups on each occasion. There were indications, however, that the sample size was adequate for the majority of analyses. The consequences, in the light of the actual sample sizes attained in the current study, will be looked at in the discussion section 4.6.1.

Of those meeting the inclusion criteria, all consenting participants were recruited. It was not possible to gather information on those individuals who chose not to participate, as they had not signed the consent forms permitting access to their medical records. Out of 70 individuals approached by a case manager to take part, 22 refused. A further three participants withdrew from the study after the interview had begun, indicating that they found answering the questions too difficult. None of those participating were so distressed by the interview as to require the researcher to speak to his or her case

manager.

2.2.4 Case manager ratings

Case managers who made ratings of the participants on the relevant measures were required to have known each individual for at least one year and to have been in contact with them at least fortnightly.

2.3 Measures

The structured interview format incorporated a series of measures and questions to elicit information, as described by the interview procedure (Appendix 8). The aim of the interviews was to explore the main variables and to review factors related to the extent of identification as either a community member or a psychiatric patient.

i) Socio-demographic information

A) Socio-demographic information was obtained from each participant's case notes. This included age, diagnosis, length of contact with psychiatric services, time spent in hospital and whether or not they took their prescribed medication (Appendix 19). Qualifications, length of employment, accommodation type and the existence of current significant relationships were also gathered from the same source.

B) Activities regularly engaged in

This was determined by asking open-ended questions to establish areas of community, as opposed to mental health service, involvement (Appendix 9). This involved gathering information on activities that participants took part in during a typical week. The activities were categorised according to whether they took place under mental health care services' provision, with the alternative being that they were activities both participated in and open to the general public (Table 8).

ii) Identity

This was established through participants' rating of: (i) themselves, (ii) a typical person living in the area and (iii) a typical psychiatric patient, on a series of 20 semantic differential scales (Appendix 11).

This measure consisted of a series of constructs, devised by Thompson (1988).

Two variables were constructed on the basis of this scale:

i) Identification with each identity category (continuous variable)

This was measured as a discrepancy score with smaller scores indicating greater identification with the identity in question (either patient or community member). The discrepancy scores were, therefore, defined within the following criteria:

- Self minus community member discrepancy score is equal to a measure of alignment with community resident identity.
- Self minus patient discrepancy score is equal to a measure of alignment with psychiatric patient identity.

ii) Grouping people according to the identity category with which participants most closely identified (categorical variable).

This enabled assignment exclusively to either the patient-identified or community-identified category.

The scoring was accomplished using an approach employed by Taylor and Perkins (1991). A score of '1', '0' or '-1' was assigned to each item for each participant. A score of '1' was given if a greater difference existed between self and community rating than between self and patient rating. A score of '-1' was given where there was a greater difference between self and patient rating than between self and community rating. A score of '0' was assigned where the differences were the same. These scores were then summed across all items to yield a total score. The total scores could range from '-20' to '20'. Participants were categorized as in the 'community member' group if they obtained a negative score and in the 'patient' group if they obtained a positive score.

iii) Rating of mental health problems

Two measures were used to establish the discrepancy between the case manager and participant's opinions relating to whether the individual had mental health problems.

A) The **Recognition of Problems** measure involved obtaining responses to the three questions: 'Do you have any mental health problems?', 'Do you believe that you need to see mental health professionals?' and 'Do you believe that you need to take medication for mental health problems?' (Appendix 10). Participants were scored according to whether their answer 'yes' or 'no' to each question, agreed with their case manager. The first question was taken from Taylor and Perkins' (1991) study and the latter two questions were added in the current study to gauge the opinions on points that pertain to what is viewed as an understanding of having mental health problems.

B) The second measure entailed reviewing disabilities associated with the individual's mental health problems. The measure employed by Taylor and Perkins (1991) was again used here. This measure was made up of six questions derived from the **Awareness of Disabilities Scale** (Thompson, 1988) (Appendix 12) which made use of four scales to rate answers to the questions (Appendices 13 to 16). The questions were asked of both the participant and the case manager.

A rating differential was established by the case manager's score being subtracted from the participant's score for each item. Negative scores were taken as implying exaggeration of disabilities relative to their case manager, where the participant was less optimistic than their case manager, and positive scores were viewed as indicating a denial of disabilities relative to the case manager, where participants were more optimistic than their case manager. Scores of zero indicated that a discrepancy did not exist between the participant and case manager's responses. The total score indicated whether overall participants denied or exaggerated their disabilities experienced, relative to the case manager's rating. The possible range of total scores was between '-20' and '+20'.

The internal consistency of the six items on the Awareness of Disabilities scale was established employing the same technique as Thompson (1991) using the Cronbach Alpha. A coefficient of 0.6 or more is regarded as indicating an acceptable level of internal consistency in an exploratory study (Nunnally, 1978), therefore the Cronbach's Alpha of 0.64 indicated that the internal consistency of the measure was acceptable, thus justifying its use in the present study. The six items on the measure were therefore used to form the scale that depicted the continuum lying between discrepancy scores indicative of the 'denial' and 'exaggeration' of disabilities relative to case manager's ratings.

Since the case managers' ratings represented a value judgement, the focus was on the rating differential. It was not considered appropriate to group the participants into 'denial' and 'exaggeration' categories as in Thompson's (1991) study. This is due to the former approach making the assumption that the case manager's ratings reflect an absolute truth, as opposed to a value judgement. Therefore, correlational analyses employed the rating differential scores. These were regarded as lying along a continuum between denial and exaggeration of disabilities relative to the case manager's ratings.

iv) Level of health and social functioning was examined using the Health of the Nation Outcome Scales (HoNOS). The HoNOS was developed for use as a Care Programme Approach measure (Wing, Curtis and Beevor, 1997; Wing, Beevor, Curtis, Park, Hadden and Burns, 1998). It was completed by each case manager. The HoNOS is a 12-item scale, with items grouped to form four subscales. The 'Behavioural' subscale consists of overactive, aggressive, disruptive or agitated behaviour, non-accidental self-injury and problem-drinking or drug-taking. The 'Functional' subscale consists of cognitive problems involving memory, orientation and understanding and problems relating to physical illness or disability. The 'Symptoms' subscale is made up of problems in relation to hallucinations and delusions, depressed mood and other mental and behavioural problems. The 'Social' subscale includes problems with inability to make supportive relationships, problems with activities

of daily living and problems with living conditions. The specific nature of each item is described in Appendix 18. The rater is instructed to focus on the individual's most severe problem within each category. Each problem area is rated from zero, indicating no clinical problem; '1' a minor to mild problem; '2' a mild to moderate problem; '3' a moderate to severe problem and '4' indicating a severe to very severe problem.

Both the subscales and the global scores were utilised. Clear cut-off points for the global score have not been established. Cut-off points used in the present study were developed by the researcher in line with what best fitted the scoring criteria for each item. For the purposes of data analysis, the following cut-off points were used:- '0' was taken to indicate no problems; '1' to '12' was taken to indicate minor to mild problems; '13' to '24' as indicative of mild to moderate problems; '25' to '36' as indicating moderate to severe problems and '37' to '48' to indicate very severe problems.

Wing et al. (1998) report that the scale's inter-rater and test-retest reliability were acceptable. The validity of the device was established by correlating it with the Brief Psychiatric Rating Scale (Overall & Gorham, 1962). A more recent study (Adams, Palmer, O'Brien & Crook, 2000) has highlighted the need for further validation studies.

v) Self-esteem was evaluated using the Rosenberg Self Esteem scale in which participants rated themselves (Rosenberg, 1965) (Appendix 17). This is a standardised measure that is well validated and with high internal reliability (Wylie, 1989). Scores provide an estimate of global self-esteem. This scale asks participants to indicate whether they strongly agree, agree, disagree or strongly disagree, with each of ten statements. Possible scores range from 10 to 40. A variety of cut-off points have been employed in the literature (Curbow and Somerfield, 1991). A cut-off of 20 was chosen in the current study to differentiate high (>20) and low (≤ 20) self-esteem.

2.4 Procedure

2.4.1 Ethical considerations

The design of the study and procedures including the data collection, were in accordance with the British Psychological Society's Ethical Principles and Guidelines (1998) and the Division of Clinical Psychology Professional Practice Guidelines (1995). Approval was gained from the local research ethics committees within each of the four Healthcare Trusts, within which the study took place (Appendices 1 to 4).

2.4.2 Recruitment procedure

Meetings were arranged with the relevant Consultant Psychiatrists and the multi-disciplinary teams within the four Healthcare Trusts within which the study was to take place.

i) Briefing procedure

Participants were approached by a member of staff who described the study using a standardised information sheet (Appendix 5). The information sheet described the nature and purpose of the study and what was expected of the participants. Those approached were informed that the information that they shared would be treated as confidential and that they had the right to withdraw at any time without this affecting their care.

For those agreeing to participate, meetings were arranged with the researcher. The researcher discussed what the interview would entail. Participants were notified that the questionnaires would be destroyed after one year. If they remained interested in participating in the study, they were asked to sign a consent form (Appendix 6). They were also asked whether they would give permission for the researcher to look at their medical notes. Where they agreed to this, the consent form for access to medical notes was presented to the participant (Appendix 7).

ii) Interview format (Appendix 8)

Participants were asked whether they wished to discuss or clarify the nature of the study. The structured interview took up to 90 minutes and was split into sessions where it was judged necessary, such as where participants experienced concentration difficulties. The interviews took place in either a room within staffed accommodation or a local clinic. The interview settings were rooms which were quiet and where interruptions were unlikely to take place.

The interview followed a set format. After each interview was completed a debriefing took place which was intended to address any concerns. The aim was that should the individual become distressed by the interview, additional time for debriefing would be available. The participant's case manager would also be informed. These provisions were not found to be necessary. Each individual's case manager was interviewed within 14 days of the participant's interview.

2.5 Data management

The distribution of data did not conform to that required for the use of parametric statistics, therefore nonparametric statistics were regarded as most appropriate. Furthermore, the other assumptions governing the use of parametric statistics (measurement on at least an interval scale and the homogeneity of variance across groups) were not fulfilled.

The data analysis involved non-parametric correlations to explore the relationships between the variables of identity and response to mental health problems and disabilities. Associations between variables were examined using the Chi-square or the Fishers Exact test. Correlations between variables were examined using the Spearman's Rho test. Differences between groups were examined using the Mann-Whitney statistical test. The Statistical Package for Social Sciences (Norusis, 1996) was used to analyse the data.

3.0 RESULTS

3.1 Hypothesis 1 : The individuals’ belief that they have mental health problems will be associated with being more closely aligned with the psychiatric patient identity.

As can be seen in Table 4, there was no association between identity and the participants’ belief that they have mental health problems (Fisher’s Exact test (df =1) = 1.87; p= 0.15). Therefore, this hypothesis is not supported. It may be observed that the results are in the predicted direction and thus may have reached significance with a larger sample of participants.

Table 4: The participants’ identity and belief that they have mental health problems

	Have mental health problems	Do not have mental health problems
Community-identified group	14 (52%)	13 (48%)
Patient-identified group	13 (72%)	5 (28%)

Note. Total N= 45

3.2 Hypothesis 2 : The individuals’ acceptance of disabilities experienced will be associated with being more closely aligned with the psychiatric patient identity.

As described in the method section 2.3, identity was measured as both a continuous and categorical variable. As a continuous variable, the identity discrepancy scores indicated the degree to which participants were aligned to each identity. These scores were used in the analysis of the present hypothesis and the results are shown in Table 5.

Table 5: Relationship between the participants’ degree of identification with identity categories and acceptance of disabilities

	rho ¹
Discrepancy between self and community member	- 0.09ns
Discrepancy between self and patient	- 0.16ns

Note. Total N= 45 ¹ rho = Spearman’s rho

No significant relationships were found between the discrepancy ratings of disabilities, taken as indicating level of acceptance of disabilities, and the identity discrepancy ratings, indicating the degree to which participants identified with each identity category. Therefore, this hypothesis is not supported. (In the above analysis, the categorical variable was not used because this does not indicate the degree to which participants identified with each identity category.)

3.3 Question 1: Are the individuals’ beliefs that they need to take medication and see healthcare professionals associated with community member or psychiatric patient identification ?

As depicted in Table 6, no association was found between the participants’ belief that they need to take medication and identity.

Table 6: The participants’ identity and their beliefs that they need to take medication and need to see healthcare professionals

	Need to take medication	Do not need to take medication
Community- identified group	18 (67%)	9 (34%)
Patient- identified group	11 (61%)	7 (39%)

Note. Total N = 45. Fisher’s Exact (df = 1) = 0.15 ns

	Need to see healthcare professionals	Do not need to see healthcare professionals
Community- identified group	20 (74%)	7 (26%)
Patient- identified group	15 (83%)	3 (17%)

Note. Total N = 45. Fisher’s Exact (df=1) = 0.54 ns

No association was found between the participants’ belief that they need to see healthcare professionals and identity.

3.4 Question 2: Role of socio-demographic variables and psychiatric diagnosis

3.4.1 Question 2 (i): Are there socio-demographic variables and diagnostic variables that are associated with the individuals’ identification as a ‘community member’ or as a ‘psychiatric patient’ ?

Table 7: Socio-demographic and diagnostic characteristics: participants grouped according to alignment with identity categories

Community member		Patient		Statistical tests	
	N	(%)	N		(%)
	27	(60)	18		(40)
Gender					
Female	9	(64.3)	5	(35.7)	Fisher's Exact (df=1) = 0.16 ns
Male	18	(58)	13	(42)	
Relationship status					
Significant relationship	7	(53.8)	6	(46.2)	Fisher's Exact (df=1) = 0.29 ns
No significant relationship	20	(62.5)	12	(37.5)	
Diagnosis					
Schizophrenia	19	(63.3)	11	(36.7)	Fisher's Exact (df = 1) = 0.42 ns
Bipolar and schizo affective disorder	8	(53.3)	7	(46.7)	
Qualifications					
With	19	(76)	6	(24)	Fisher's Exact (df = 1) = 6*
Without	8	(40)	12	(60)	
Whether working presently					
Yes	9	(75)	3	(25)	Fisher's Exact (df = 1) = 1.53 ns
No	18	(54.5)	15	(45.5)	
Living situation					
Independent	9	(75)	3	(25)	Fisher's Exact (df = 1) = 1.53 ns
Live with support ²	18	(54.5)	15	(45.5)	
Identity discrepancy scores					
Age	rho ¹ = 0.02 ns				
Length of contact with psychiatric services	rho = -0.12 ns				
Years spent in hospital	rho = - 0.23 ns				
Years worked in a job	rho = -0.31*				

¹ rho = Spearman’s rho * p < 0.05 (2-tailed)

² ‘Live with support’ category combining living with family members in day-time supported accommodation and 24-hour staffed accommodation.

Note. Identity was treated as a continuous variable. Higher scores indicate greater identification as a community member.

Identity and work-related variables

As can be seen in Table 7, a positive association was found between identity and qualifications. This indicated that patient-identified participants tended not to have qualifications. Out of those with qualifications, it was found that 60 per cent had acquired them prior to first becoming unwell with mental health problems. In relation to age of illness onset, for the patient-identified group the median age was 21 years and for the community-identified group the median age was 25 years.

A negative association was found between identity and years worked in a job, such that community-identified participants tended to have worked for a number of years in a job.

There was no association found between identity and either gender, relationship status, whether the participants were working presently, living situation or diagnosis. There was also no association found between identity and either age, length of contact with services or number of years spent in hospital.

3.4.2 Participants grouped according to alignment with identity categories : day-time activities

Table 8 summarises activities which participants reported taking part in during a typical week.

Each participant could take part in more than one activity, thus the numbers in Table 8 refer to the number of participants taking part in each activity. This was not investigated statistically due to participants being able to be represented more than once (thus not meeting the assumption of independent observation), through each being able to name more than one activity that they participated in. The total number of activities participants reported taking part in ranged between zero and six activities across both groups of activities.

Table 8: Identity groups and participation in community and psychiatric service-related activities

	Community-identified group (N = 27)	Patient-identified group (N = 18)
	Number of individuals participating in each activity	Number of individuals participating in each activity
Community-related activities		
Job	9	3
Vocational course	2	2
Course out of interest	2	2
Leisure centre	3	0
Church	3	5
Library	13	2
<i>Total number of times this group of activities participated in</i>	32	14
% of total number of activities participated in	57	38
Service-related activities		
Day Centre	11	11
Social club/Drop-in	12	11
Club House	1	1
<i>Total number of times this group of activities participated in</i>	24	23
% of total number of activities participated in	43	62

Note. Total N = 45

The results are interesting since, as would have been expected, out of the activities reported community-identified participants described taking part in a larger proportion of community-related activities, whereas for the patient-identified group a larger proportion of service-related activities were participated in.

3.4.3 Question 2 (ii) (1) : Are there socio-demographic variables and diagnostic variables that are associated with the individuals’ belief that they have mental health problems?

There was no significant association found between participants’ belief that they have mental health problems and either gender, relationship status, diagnosis, having qualifications, whether working presently or living situation.

Table 9: Socio-demographic and diagnostic characteristics : participants grouped according to their belief that they have mental health problems

	Do have mental health problems	Do not have mental health problems	Statistical tests
	N (%)	N (%)	
	27 (60)	18 (40)	
Gender			Fisher's Exact (df = 1) = 1.1 ns
Female	10 (71.4)	4 (28.6)	
Male	17 (54.8)	14 (45.2)	
Relationship status			Fisher's Exact (df = 1) = 1.1 ns
Significant relationship	9 (69.2)	4 (30.8)	
No significant relationship	18 (56.3)	14 (43.7)	
Diagnosis			Fisher's Exact (df = 1) = 0.75 ns
Schizophrenia	14 (45.2)	17 (54.8)	
Bipolar and schizoaffective disorders	13 (92.8)	1 (7.2)	
Qualifications			Fisher's Exact (df = 1) = 0.38 ns
With	16 (64)	9 (36)	
Without	11 (55)	9 (45)	
Whether working presently			Fisher's Exact (df = 1) = 0.02 ns
Yes	7 (58.3)	5 (41.7)	
No	20 (60.6)	13 (39.4)	
Living situation			Fisher's Exact (df = 1) = 0.9 ns
Independent	6 (75)	2 (25)	
Live with support	21 (56.8)	16 (43.2)	
	Median (range)	Median (range)	
Age	45 (28 – 65)	48.5 (34 – 62)	U [†] = 189.5 ns
Length of contact with psychiatric services (years)	20 (10 – 43)	20.5 (10 - 36)	U = 203.5 ns
Years spent in hospital	2.92 (0.31 - 23.4)	3.21 (0.48 - 12.5)	U = 226 ns
Years worked in a job	4 (0 - 29)	10 (0 - 27)	U = 202.5 ns

* p < 0.01 (2-tailed)
[†] Mann-Whitney U test

There was no difference found between the group who believed and who did not believe that they had mental health problems, in terms of the groups’ age, length of contact with services, years spent in hospital or years worked.

3.4.4 Question 2 (ii) (2): Are there socio-demographic variables and diagnostic variables that are associated with the individuals’ belief that they need to take medication ?

Table 10: Socio-demographic and diagnostic characteristics : participants grouped according to the belief that they need to take medication

	Do need to take medication	Do not need to take medication	Statistical tests
	N (%)	N (%)	
	29 (64.4)	16 (35.6)	
Gender			Fisher’s Exact (df = 1) = 0.43 ns
Female	10 (71.4)	4 (28.6)	
Male	19 (61.3)	12 (38.7)	
Relationship status			Fisher’s Exact (df = 1) = 0.067 ns
Significant relationship	8 (61.5)	5 (38.5)	
No significant relationship	21 (65.6)	11 (34.4)	
Diagnosis			Fisher’s Exact (df = 1) = 0.0004 ns
Schizophrenia	19 (63.3)	11 (36.7)	
Bipolar and schizoaffective disorders	10 (62.5)	6 (37.5)	
Qualifications			Fisher’s Exact (df = 1) = 0.005 ns
With	16 (64)	9 (36)	
Without	13 (65)	7 (35)	
Whether working presently			Fisher’s Exact (df = 1) = 0.04 ns
Yes	8 (67)	4 (33)	
No	21 (63.6)	12 (36.4)	
Living situation			Fisher’s Exact (df = 1) = 0.11 ns
Independent	5 (62.5)	3 (37.5)	
Live with support	24 (64.9)	13 (35.1)	
	Median (range)	Median (range)	
Age	46 (28 – 63)	47.5 (32 – 67)	U = 205 ns
Length of contact with psychiatric services (years)	22 (10 – 43)	19.5 (10 - 43)	U = 228.5 ns
Years spent in hospital	2.92 (0.42 - 14.58)	3 (0.48 - 23.42)	U = 229 ns
Years worked in a job	6 (0 - 29)	9.2 (1 - 28)	U = 180.5 ns

As can be seen from Table 10, there were no significant associations between the participants’ belief that they need to take medication and gender, relationship status, qualification, whether they work presently, living situation and diagnosis. There were also no differences between groups in terms of

age, length of service contact, years in hospital or years worked.

3.4.5 Question 2 (ii) (3) : Are there socio-demographic variables and diagnostic variables that are associated with the individuals’ belief that they need to see healthcare professionals ?

Table 11: Socio-demographic and diagnostic characteristics : participants grouped according to their belief that they need to see healthcare professionals

	Do need to see healthcare professionals		Do not need to see healthcare professionals		Statistical tests
	N	(%)	N	(%)	
Number of participants	35	(77.8)	10	(22.2)	
Gender Female Male	14 21	(100) (67.7)	0 10	(0) (32.3)	Fisher’s Exact (df= 1) = 5.86 *
Relationship status Significant relationship No significant relationship	11 24	(84.6) (75)	2 8	(15.4) (25)	Fisher’s Exact (df= 1) = 0.495 ns
Diagnosis Schizophrenia Bipolar and schizoaffective disorders	22 13	(73.3) (86.7)	8 2	(26.7) (13.3)	Fisher’s Exact (df=1) = 1.03 ns
Qualifications With Without	17 18	(68) (90)	8 2	(32) (10)	Fisher’s Exact (df=1) = 3.12 ns
Whether working presently Yes No	9 26	(75) (78.8)	3 7	(25) (21.2)	Fisher’s Exact (df= 1) = 0.07 ns
Living situation Independent Live with support	6 29	(75) (78.4)	2 8	(25) (21.6)	Fisher’s Exact (df= 1) = 0.04 ns
	Median (range)		Median (range)		
Age	46 (28 - 65)		45 (33 - 63)		U = 163.5 ns
Length of contact with psychiatric services (years)	23 (10 - 43)		18 (10 - 35)		U = 132 ns
Years spent in hospital	3.7 (0.42 - 23.42)		1.75 (0.42 - 3.75)		U = 84 *
Years worked in a job	7 (0 - 29)		10 (1 - 24)		U = 171 ns

* p < 0.05

Participants' belief that they need to see healthcare professionals and gender

An association was found between the participants' belief that they needed to see healthcare professionals and gender, such that all female participants believed that they did need to see healthcare professionals.

Participants' belief that they need to see healthcare professionals and years spent in hospital

There was a difference found between the groups who believed that they did need to see healthcare professionals and those who believed that they did not in terms of years spent in hospital, such that participants who believed that they needed to see healthcare professionals had experienced a greater number of years hospitalised. This result may initially appear unsurprising, however it is important to consider that hospital admissions for individuals with SEMH problems can include being sectioned under the mental health act and being admitted against their will, which may not always be conducive to an acceptance of the involvement of healthcare professionals in their lives.

3.4.6 Question 2 (iii) : Are there socio-demographic variables and diagnostic variables that are associated with the individuals’ view of their disabilities experienced?

Table 12: Socio-demographic and diagnostic characteristics: participants’ view of their disabilities

	View of disabilities: disability discrepancy scores (continuous variable)	Statistical tests
	Median (range)	
Gender Female Male	6 (-3 - 15) 6 (-15 - 18)	U = 210 ns
Relationship status Significant relationship No significant relationship	6 (-10 - 15) 5.5 (-15 - 18)	U = 196 ns
Diagnosis Schizophrenia Bipolar and schizoaffective disorders	6 (-15 - 17) 4 (- 4 - 18)	U = 138 ns
Qualifications With Without	8 (-10 - 18) 4.5 (-15 - 14)	U = 169 ns
Whether working presently Yes No	7 (- 4 - 13) 5 (-15 - 18)	U = 186 ns
Living situation Independent Live with support	2.5 (-10 - 18) 4.2 (- 4 - 17)	U = 116 ns
	Disability discrepancy score	
Age	rho = - 0.19 ns	
Length of contact with psychiatric services (years)	rho = - 0.14 ns	
Years spent in hospital	rho = 0.18 ns	
Years worked in a job	rho = - 0.05 ns	

Note. The negative scores indicate an exaggeration of disabilities and positive scores indicate a denial of disabilities.

As can be seen in Table 12, there were no differences found between groups in terms of their age, relationship status, diagnosis, qualifications, whether working presently, living situation and the participants’ view of their disabilities. No association was found between the participants’ view of their disabilities and age, length of service contact, years spent in hospital and years worked.

3.5 Question 3: Role of health and social functioning

3.5.1 Question 3 (i): Is level of health and social functioning associated with the individuals' identification as a 'community member' or as a 'psychiatric patient'?

Identification and overall level of functioning

As shown in Table 13, there was an association found between the participants' identification and the HoNOS total score representing their overall level of functioning, such that patient-identified participants received scores indicative of greater problems in their overall level of functioning. There was an association between identity and overactive, aggressive, disruptive or agitated behaviour, such that patient-identified participants received high scores indicative of their exhibiting greater rates of this behaviour.

3.5.2 Question 3 (ii) (1): Is level of health and social functioning associated with the individuals' belief that they have mental health problems ?

There were no associations found between the participants' belief that they had a mental health problem and their HoNOS total scores received and each of the HoNOS subscales.

3.5.3 Question 3 (ii) (2): Is level of health and social functioning associated with the individuals' belief that they need to take medication ?

There was an association found between the participants' belief that they needed to take medication the HoNOS total score, such that those who believed that they did not need to take medication received scores indicative of greater problems in their overall level of functioning.

3.5.4 Question 3 (ii) (3): Is level of health and social functioning associated with the individuals' belief that they need to see healthcare professionals ?

There were no associations found between the participants' belief that they needed to see healthcare professionals and the HoNOS total or subscale scores.

Table 13 : Participants' health and social functioning and the main variables

	rho
Identity (continuous variable)	
HoNOS total score	0.29*
HoNOS subscales:	
Behaviour	0.36
Functional	0.13
Symptoms	0.21
Social	0.02
Individual HoNOS item: Overactive, aggressive, disruptive or agitated behaviour	0.42 **
Participants' belief that they have mental health problems	
HoNOS total score	0.017
HoNOS subscales:	
Behaviour	-0.03
Functional	0.05
Symptoms	-0.06
Social	0.26
Participants' belief that they need to take medication	
HoNOS total score	0.34*
HoNOS subscales:	
Behaviour	0.19
Functional	0.27
Symptoms	0.25
Social	0.14
Participants' belief that they need to see healthcare professionals	
HoNOS total score	0.16
HoNOS subscales:	
Behaviour	-0.002
Functional	-0.08
Symptoms	0.05
Social	0.17
Participants' view of disabilities experienced (continuous variable)	
HoNOS total score	0.36*
HoNOS subscales:	
Behaviour	0.28
Functional	-0.08
Symptoms	0.26
Social	0.27

* p < 0.05 (2-tailed) **Bonferroni correction employed, so p < 0.00417 (2-tailed) Note. Total N= 45.

Analyses were also carried out of the individual HoNOS items but, as can be seen from the Table 13, only one reached a level of statistical significance subsequent to the Bonferroni corrections.

3.5.5 Question 3 (iii): Is level of health and social functioning associated with the individuals' view of their disabilities experienced ?

View of disabilities and general level of health and social functioning

As shown in Table 13, there was a positive association between ratings of disabilities discrepancy scores and the total HoNOS scores. Thus, participants who expressed a 'denial' of their disabilities¹ were rated as having problems with their overall functioning.

3.6 Question 4: Role of self-esteem

Table 14: Participants' self-esteem and the main variables

	rho
Identity (continuous variable)	0.2
Participants' belief that they have mental health problems	-0.13
Participants' belief that they need to take medication	0.14
Participants' belief that they need to see healthcare professionals	-0.7
Participants' view of disabilities experienced (continuous variable)	-0.35 *

* p < 0.05

3.6.1 Question 4 (i): Is self-esteem associated with the individuals' identification as a 'community member' or as a 'psychiatric patient'?

As can be seen from Table 14, no relationship was found between the participants' identity and their self-esteem.

¹“Denial’ of disabilities’ shall be used in the following text to refer to positive scores implying a participant’s denial of disabilities relative to their case manager.

3.6.2 Question 4 (ii) (1) : Is self-esteem associated with the individuals' belief that they have mental health problems?

No relationship was found between the participants' beliefs that they had mental health problems and their self-esteem.

3.6.3 Question 4 (ii) (2) : Is self-esteem associated with the individuals' belief that they need to take medication ?

No relationship was found between the participants' belief that they needed to take medication and their self-esteem.

3.6.4 Question 4 (ii) (3): Is self-esteem associated with the individuals' belief that they need to see healthcare professionals ?

No relationship was found between the participants' belief that they needed to see healthcare professionals and their self-esteem.

3.6.5 Question 4 (iii): Is self-esteem associated with the individuals' view of their disabilities experienced ?

There was a negative relationship between the participants' view of their disabilities and their self-esteem, such that those denying their disabilities tended to have high self-esteem

3.7 Other results of interest

Due to the current study being of an exploratory nature, further unplanned analyses were carried out to inform a better understanding of the relationship between the key variables. The variables that reached a level of statistical significance are reported.

‘Overactive behaviour²’ and mental and behavioural problems

An association was found indicating that ratings of greater problems relating to ‘overactive behaviour’ on the HoNOS were related to receiving ratings of greater difficulties relating to ‘other mental and behavioural problems’.

Table 15: Other results of interest

	rho
	‘Overactive behaviour’ (HoNOS)
Mental and behavioural problems (HoNOS)	0.44 **
	Self-esteem
Years spent in hospital	-0.36 *

* $p < 0.05$ ** Bonferroni corrections employed, so $p < 0.00417$ (2-tailed) *Note.* Total N = 45

Self-esteem and years spent in hospital

Participants’ self-ratings of low self-esteem was associated with the experience of a greater number of years spent in hospital.

² ‘Overactive behaviour’ shall be used in the following text to refer to ‘overactive, aggressive, disruptive or agitated behaviour’

4.0 DISCUSSION

The results from this study in terms of identity, participants' beliefs that they have mental health problems, need medication or need to see healthcare professionals and their view of their disabilities will be discussed and compared with previous research findings. Following this, the wider implications of the results will be explored before discussing the potential limitations within the method and measures.

4.1.1 Summary of results

The results suggested that neither participants' belief that they have mental health problems nor acceptance of disabilities were associated with identity, as measured in this study. Therefore, the two central hypotheses, concerning the relationship between identity and both participants' beliefs that they have mental health problems and disabilities, must be rejected. This lends support to Taylor and Perkins' findings that an identification as a community member or a patient is unrelated to acknowledging having mental health problems or disabilities.

The participants' identification did not correlate with recognition of either need for medication or need to see healthcare professionals, indicating that these variables were unrelated. The participants' identification as a community member was associated with high overall health and social functioning, low 'overactive behaviour', having qualifications and having worked for a number of years in a job.

The participants' belief that they needed to take medication was associated with overall functioning at a high level and the belief that they needed to see healthcare professionals was associated with female gender and more years spent in hospital. Participants' denial of disabilities was associated with low overall health and social functioning and high self-esteem

4.1.2 The participants in the current study in comparison with Taylor and Perkins' study

The group of participants was mainly male, European, with a diagnosis of schizophrenia, with most of the group (60 per cent) accepting that they had mental health problems. The proportion who believed that they had mental health problems was higher than the 47 per cent in Taylor and Perkins' (1991) study. In the current study, forty per cent of the participants identified most closely with a psychiatric patient, which is very similar to Taylor and Perkins' findings within which 41 per cent of participants indicated an identification as a patient. Thus, most of the participants in the current study (60 per cent) identified most closely with members of the general community.

The participants had been in hospital for four years on average, over an average of a 22 year history of psychiatric service contact. This was in contrast to Taylor and Perkins' sample, who had been in hospital for an average of 11.2 years within an average of 24.6 years of contact with services overall. Thus, this supports participants in the current study as generally having had different experiences of healthcare services, through having been maintained in the community for longer periods of time in between hospitalisations. The results shall now be discussed.

4.2 The participants' identification

In the current study patient-identified participants exhibited 'overactive behaviour', which runs parallel to Taylor and Perkins' findings within which 'challenging behaviour' was exhibited by patient-identified individuals. Indeed, the expectations and reactions of relatives, staff and the public to an individual as if they are permanently symptomatic, could have contributed to the individual's identification as a patient. In support, Barham and Hayward (1995) hypothesised that it is other people's perception of people with SEMH problems that results in their being devalued and excluded from membership of wider society.

In terms of understanding ‘overactive behaviour’, as can be seen in the results section (Table 15), this was associated with ‘mental and behavioural problems’, which includes anxiety, phobias, eating and sleeping problems, thus difficulties in relation to one of these areas may have impacted on the other. There may, therefore, be a variety of symptoms that underlie difficulties in relation to ‘overactive behaviour’.

The tendency for community-identified participants to have qualifications could be due to their levels of ability and disabilities. As was reported in the results, out of those with qualifications 60 per cent had gained them prior to their illness. This could represent a pre-illness experience that may have contributed to maintaining an identification as a community member. Community-identified participants’ greater likelihood of having had the socially valued experiences, in having gained qualifications and employment, could be understood in terms of the individual’s premorbid functioning and what he or she had in their life prior to their illness. This may have contributed to the individual having a more cohesive sense of self subsequent to their illness that could have bolstered them against the disadvantages of having SEMH problems.

In summary, it would appear that current overall level of health and social functioning, qualifications gained and years worked, may be pertinent in their contribution to an identification as a patient or a community member. Equally, the individual’s pre-morbid level of functioning, sense of self and current experience of socially valued life events may each have contributed to their identification.

4.3 The participants’ belief that they have mental health problems, need to take medication and need to see healthcare professionals

There was no significant association found between the participants’ belief that they had mental health problems and other variables. Participants who believed that they did not need to take medication tended to be functioning at a lower level, in terms of their general health and social functioning. Since

all participants were reported to be taking their medication at the time of interview, belief about medication was not affecting compliance with medication. However, the poor level of functioning may have impacted on their perception of the lack of benefit gained from using medication.

All female participants expressed believing that they needed to see healthcare professionals. This finding is supported by research indicating that women tend to make greater use of community support for mental health problems than men (Kulkarni, 1997). The participants' belief that they needed to see healthcare professionals was also associated with experiencing a high number of years in hospital. This could indicate that either more time in hospital enhances an individual's recognition of their need for support or that recognition of need for support influences time spent in hospital. Equally, support from healthcare professionals in the community setting may be preferable to a hospital admission or could confirm the need for hospital admissions.

In summary, it would appear that an individual's level of functioning may have impacted on or been affected by their belief about the need for medication. Also, time in hospital may have affected and, or, been affected by their view of the need for healthcare professional involvement in their lives.

4.4 The participants' view of their disabilities

The relationship between disabilities discrepancy ratings and other variables supported some of Shepherd's (1984) predictions in his 'denial-sick role' dichotomy. This includes the prediction that individuals who 'exaggerated' their disabilities would have lower self-esteem, which could be associated with the individual preserving his or her sense of dignity. The relatively higher level of self-esteem in those 'denying' disabilities was a repetition of Taylor and Perkins' (1991) findings and could support denial as serving a defensive function in response to disabilities experienced.

In the current study, in relation to low self-esteem, this was associated with the experience of a greater

number of years spent in hospital. This relates to Breakwell's (1986) proposal that it is the social representation of needing to be hospitalised for having SEMH problems with the associated loss of status and marginalisation that is a threat to the individual's self-esteem.

In terms of higher duration of contact with mental health services, this study did not find that this was associated with denial of disabilities, as was found within Taylor and Perkins' study. The disparity in the length of hospitalisations between the participant groups in the current and Taylor and Perkins' study may partly explain some of the different findings.

In summary, life experiences prior to illness indicated that both differences in levels of ability as well as each individual's access to socially valued experiences may have affected an individual's identity. Variables associated with self-esteem indicated the existence of potential defensive responses to the existence of disabilities. Overall, the 'exaggeration' of disabilities in the current study appeared to function to preserve the individual's dignity and 'denial' may have protected the individual from acknowledging the implications of the reality of difficulties experienced impacting on their self-worth.

4.5.1 The clinical relevance of the findings

The ways in which the current findings can inform the conceptualisation of response to having SEMH problems shall now be addressed prior to reviewing their implications for clinical practice.

Findings from previous research studies have yielded conflicting results. Studies have supported a relationship between responses to mental illness and identity (Thompson, 1988; Bender and Pilling, 1985), while another study found that these variables were unassociated (Taylor and Perkins, 1991). The different results across the research studies could reflect the different populations studied, with the psychiatric services at different stages in the development of community care.

The current results allow the development of speculations about the processes underlying responses to living with SEMH problems. The greater rates of problems with overall health and social functioning and 'overactive behaviour' relating to identification as a patient, suggest that this is particularly disabling for individuals. They could, however, each relate to how individuals are made to feel through their interactions with services, their families and the general public. Such interactions can impact on identity adopted regardless of their belief that they have problems, or may influence their acknowledgement that they have problems in spite of their identity.

The results could suggest that individuals, through splitting off their illness from their self such as through regarding the illness as an aspect of an 'unreal self', accepting the mental illness and associated disabilities would not impact negatively on their identity. This supports Taylor and Perkins' (1991) hypothesis relating to an individual's ability to 'compartmentalise' their illness.

The premorbid level of social and intellectual functioning and socially valued life events prior to illness could determine a more solid sense of self, so serving to bolster the individual's ability to cope with stressful life events subsequent to illness. It is also possible that once having experienced a SEMH problem, having socially valued life experiences, such as gaining qualifications and working, could legitimise an individual's sense of identity as more aligned to that of a community member or could reduce the likelihood of an identification as a patient.

Self-esteem was indicated as important in underlying 'denial' of disabilities. The relationship between denial of disabilities and higher self-esteem could lend support to denial serving to minimise damage to the individual's self-worth. Therefore, the impact of contemplating that one has mental health problems on one's self-esteem could potentially play an important part in the response to having a SEMH problem.

To summarise, the central findings highlighted the lack of a relationship between identity and response to problems and, thus, how unhelpful it is to make the assumption that these variables are related. Clinically, the findings from the current study do not appear to contribute to an understanding of the functional significance of identity in terms of the manifestation of and ‘recovery’ from ‘mental illness’. The measure of identity used in this study may not have been sufficient to be able to support explanations required. This would appear to need addressing through further research on this complex and dynamic concept, which shall be returned to for discussion in section 4.7. The results do, however, implicate potentially important processes which may need to be considered in tailoring approaches to working with an individual.

4.5.2 The implications of the findings for clinical practice

It was hoped that the current study’s findings would provide insight into processes that are critical to informing clinical approaches to enhance an individual’s recovery and improve their quality of life. Due to the sample size and heterogeneity of individuals who have SEMH problems, the implications for clinical practice shall be made tentatively.

The results draw attention to the importance of framing the individual’s needs separately in terms of the way in which an individual thinks about him or herself as a result of having SEMH problems and the way in which they respond to having these problems. This study would support the importance of addressing the individual’s responses to problems with sensitivity. Denial of disabilities could be viewed as a stage in adaptation, in learning to live with SEMH problems, prior to their being accepted which may prove to be a more demanding stage for the individual (Taylor, 1989). Thus, denial could potentially protect individuals who experience high levels of disability.

It is possible that a sense of ‘shock’, in response to the catastrophic experience of the illness and symptoms, resulting in denial, could allow the individual to process the information in a non-emotional and intellectual manner. Through progress in the processing of this information and the development

of coping strategies, the individual may be able to make a transition in their acceptance of problems experienced. This conceptualisation of denial informs an understanding of its function that underlines the importance of being sensitive to its existence and the value of exploring strategies to cope with having a stigmatised problem, distressing symptoms and disabilities.

This study's findings in relation to self-esteem appeared to focus on the role of defensive responses to disabilities. This highlights the value of cognitive approaches to alter an individual's stigmatising and self-denigrating beliefs that result from the stigma attached to having a mental health problem which can hinder the individual's progress towards recovery (Hayward and Bright, 1997). Clinical work, focussing on increasing awareness of positive qualities and enhancing socially valued experiences, whilst reviewing underlying biases in perception and self-critical thinking, could be influential in enhancing an individual's self-esteem (Fennell, 1999).

Since denial has the potential to create or maintain disabilities, for example through reducing the individual's likelihood of practising important life skills, this implicates the value of developing practical approaches to enhance an individual's confidence and limit their avoidance of taking up a challenge. Thus, the individual with SEMH problems may be supported in incorporating into their life purposeful activities (Davey, 1999). The development a number of alternative competent roles, could then help to counteract handicaps imposed by others. Where appropriate work, through boosting status, personal achievement and structure, may be invaluable in enhancing self-esteem and limiting disabilities in this group. This emphasises the importance of specialist flexible work schemes to bridge the gap between work and unemployment (Schneider, 1998). At the service level, individuals may be encouraged to develop constructive relationships with local communities, through being supported to advocate for themselves and linking up with local groups, such as colleges (Sayce and Willmot, 1997).

The findings would indicate the importance of working to educate the public about experiences of living with SEMH problems, to aim to limit the profoundly handicapping stigma experienced by individuals concerned. This needs to incorporate exposure of the public to individuals with SEMH problems, which could include their involvement in promoting positive messages to the public, such as through working as consultants to influence the development, setting up and management of services and legislation developments (Campbell,1999).

The individual's unique personal reactions to illness and their social disabilities experienced may be helpful in informing treatment protocols. In this study, socially disabling problems included 'overactive behaviour' as pertinent to patient-identified participants. Through such behaviours potentially restricting both access to community activities, opportunities to form relationships and possibly life choices, this would appear to be vital to address through a functional analysis of the behaviour.

This study would appear to indirectly support the value of clinical work at the level of the family, staff and healthcare system. The results of the current study suggest that the way that people are made to feel through the way that they are perceived by others is powerful in threatening the individual's sense of competency and adaptive response to having a SEMH problem. Psychological support could involve exploring this sensitively with staff and relatives. This could incorporate a psychoeducational approach in the application of psychological knowledge to help family and staff to review alternative ways of framing the individual's difficulties (Fadden, 1997; Smith and Birchwood, 1990). This approach could promote the avoidance of pathologising forms of distress which lie outside of the prevailing norm and actively exploring their beliefs about illness and SEMH problems. Interventions would need to be integrated into existing services, as part of a long-term package of care.

Prior to considering speculations for future research, a number of limitations need to be borne in mind when considering the results of this study.

4.6.1 Analytic and statistical issues

Non-parametric tests were used to analyse the data collected in this study. While this had the disadvantage of being less statistically powerful than parametric analyses, fewer assumptions about the nature and distribution of the data are made by these tests.

Since the large number of statistical tests conducted increased the probability of spuriously statistically significant findings occurring through chance, Bonferroni corrections were used to adjust for inflation of type I error. The correlations that reached significance were of a modest size, between 0.3 to 0.4, tending to account for nine to sixteen per cent of the variance, which left up to 91 per cent unaccounted for. With this in mind, results have been interpreted with appropriate caution and attention has been paid to the pattern of results, so that excessive emphasis has not been placed on any one finding.

None of the between-groups analyses, relating to identity and participants' belief that they have mental health problems, need medication or need to see healthcare professionals, reached significance, which could relate to the sample size required to gain the expected effect size of 0.024, which was 1000 participants in each group. It was difficult to be conclusive about these findings in the current study, which could be due to either a small effect that is undetectable due to the low power of the study, or there being no effect. Although there were indications that for the majority of analyses the sample size was probably adequate, this supports the importance of being tentative about the findings of the current study.

The data were not subjected to more sophisticated analyses, such as regression analysis, due to the small sample size. The significance level and the modest sample size imply that the results should be cautiously stated and tentatively accepted. The aim was that this study was to provide the basis for further research.

4.6.2 Discussion of method

The lack of randomised sampling, although limiting the findings' generalisability, reflected the reality of much research within clinical psychology and psychiatry, in terms of the difficulty selecting a random sample from a population (Kraemer, 1981). Considering the small number of participants meeting the criteria for the study, it would have been inappropriate to have randomly selected and rejected participants from the available pool. Yet, to have increased the sample pool would have been practically and financially prohibitive.

In terms of the findings' external validity, the results were viewed as most typical of and relevant to European males with a diagnosis of schizophrenia, who made up the largest proportion of the population sample in the present study. In relation to generalisability across time, the current study is distinct from previous studies which derived their data in an era that had different emphases in terms of culture of care for people with SEMH problems.

Potential limitations that could impact on conclusions that could be drawn from this study's results include the extent to which the attrition rate could have introduced a bias into the sample. This includes individuals who denied their difficulties being more likely to be more wary about discussing how they viewed their problems and less inclined to take part in the study. It would, therefore, have been of value to have interviewed individuals who were more sensitive or wary about discussing their mental health. Details about those individuals who chose not to participate could have thrown some light on their characteristics, however for ethical reasons it was not possible to gather information on this group.

Other problems evident within the research design included the limitations of closed questions. Such questions could potentially be understood differently by different participants. To enhance consistency in the understanding of the questions, the individual's understanding of questions was clarified and prompts used where appropriate. Closed questions introduced a methodological advantage through

being standard and consistent, so tapping into the area of interest in a consistent manner, hence enhancing the ability to compare answers across the group. In practice, this kept the interview within time constraints, so limiting the effects of fatigue, which could have impacted on concentration.

Other potential methodological issues include social desirability effects (Crowne and Marlowe, 1964). Participants may have responded with answers that they believed the interviewer wished to receive, or in accordance with their wish to present themselves in a positive light. Although partly addressed through the participants being told that their answers would be held in confidence and that their responses would not be identifiable in the final research thesis, this nevertheless remained a potential limitation.

4.6.3 Issues concerning measures used

As far as was possible standardised measures and measures employed in previous research, were selected for use. The measure of identity involved allocating participants to the category they most closely identified with. This entailed the discrepancy scores between each individual's own rating of self compared to their ratings of the other two categories. This was the means by which participants were categorized in Taylor and Perkins' (1991) study. This approach takes into account individual differences in the perception of the different identity categories. Since identity may be viewed as existing along a continuum, it appeared to be oversimplified to just make use of categories. Therefore, further analyses were employed that looked at degree of identification with each category.

In order to establish individuals' responses to their problems, Taylor and Perkins (1991) grouped individuals according to their combined response to the recognition of having a mental health problem and the Awareness of Disabilities measure. In the present study, these measures were viewed separately, since they were regarded as appraising separate areas. Indeed, recognition of having problems was regarded as comprising various components. Therefore, to address this, the questions relating to need for medication and need to see healthcare professionals were also asked.

In the current study the analysis of the Awareness of Disabilities measure differed from the way in which it had been used by Taylor and Perkins (1991), who used the measure to create two groups, that of ‘deniers’ and ‘exaggerators’. Thus, it was not deemed appropriate to group participants, instead discrepancy rating scores were treated as lying along a continuum between what was taken to represent the ‘denial’ and ‘exaggeration’ of disabilities relative to each case manager’s rating. However, this method of reviewing awareness of disabilities did not take into account how it is not uncommon for people to hold contradictory views simultaneously, in both ‘denying’ and ‘exaggerating’ their disabilities experienced. Thus, this was a very crude evaluation of the acknowledgement of disabilities.

The range of HoNOS total ratings across the groups indicated that most participants appeared to have problems within the minor to mild range. Considering the participants’ diagnoses, evidence of problems of greater severity may have been expected. The distribution of total scores on the HoNOS suggested that this measure may have had limited sensitivity with this group. This is despite the HoNOS measure having been designed to use with people with mental health problems. However, as discussed in the method section 2.2.2, the measure has not demonstrated sensitivity to problems within people with SEMH problems who are not in an acute episode of illness.

4.6.4 Issues raised in the research interview

A range of observations was made during the administration of the measures. Firstly, the Awareness of Disabilities measure was actually a measure of the level of concordance between participant and case manager. This had clinical relevance, through reflecting a mediating factor apparent in individuals’ interactions with the healthcare services, in their response to and acceptance of support and treatment.

The question ‘Do you believe that you have mental health problems?’ elicited a range of responses that may have been indicative of the complexity of this question. Responses to this question included comments such as,

‘I have had mental illness in the past, but I don’t consider myself to have a mental health problem presently’.

Such responses indicated a sense of reluctance about accepting that they had chronic mental health problems. This highlighted the importance of asking the further questions about disabilities, need for medication and need to see healthcare professionals to clarify this further. Participants’ answers to the question ‘Do you believe that you need to take medication for mental health problems?’ often tended to include comments such as,

‘I know I have to take medication, I have no choice, I suppose I have to accept it. It makes for an easier life to take it. So yes, I do accept my medication’.

Such responses indicative of ambivalence again highlighted the value of asking the additional questions to gauge the individual’s beliefs relating to having mental health problems.

The question asked of case managers, from the Awareness of Disabilities measure: ‘How much would you say that mental health problems are a burden for the individual?’, needed clarification. This required differentiating between how the case manager perceived the participant’s view of the burden from how the case manager perceived the burden themselves.

The semantic differential scales, as part of the identity measure, included the constructs ‘cooperative - uncooperative’, which was viewed as unhelpful by the interviewer, due to its implications in relation to power differentials between staff and clients. However, to ensure comparability with previous research studies, the constructs were retained.

4.7 Development of theories and future research

In the literature reviewed in the current study the concept of identity was given a central role in understanding experiences of living with a chronic mental health problem. Various theorists hypothesized that there would be a relationship between identity and the individual’s acceptance that

they had a SEMH problem, mediated by societal pressures and prejudices. This study has called into question some of the assumed relationships. The current study did not find identity, as measured, to be pivotal or predictive.

On the basis of the data from the present study, it could be hypothesized that identity has a dynamic relationship with the severity and disruptiveness of the problems an individual experiences. Identity would also appear to have a dynamic relationship with the degree to which an individual acknowledges and denies these problems. Classical empirical approaches and commonly employed statistical techniques would not appear to be ideally suited for investigating or capturing the nature of the dynamic interactions. More innovative methodologies would need to be explored and developed so that significant advancements can be made in our understanding of this area.

Qualitative methods could be used to explore an individual's perceptions of which variables are relevant, their salience and how they relate to and interact with one another. Grounded theory could involve interviewing people to ascertain their conception of what it means to have a diagnosis of psychosis and to live with symptoms and disabilities associated with mental health problems. This could address the potential for individuals to simultaneously both deny and exaggerate disabilities that they experience.

This study highlights the value of continued exploration of what enables individuals with SEMH problems to survive in the community and aspects such as social experiences or areas of functioning that operate as buffers. Qualitative methodology could be employed to look at the range of possible coping responses and levels of acceptance. Detailed interviews could aim to clarify responses towards each person's experience of different aspects of mental health problems and disabilities.

The way in which individuals make the adjustment to having SEMH problems could be reviewed

through qualitative interviews within a longitudinal design, to allow detailed exploration of changes in how individuals are made to feel through their interactions with others. This could inform an understanding of the relationship between functioning and other components in the individual's life that contribute to recovery. Also this could enable the dynamic relationship between life events, changes in appraisals and coping styles to be examined.

4.8 Conclusions

Findings from this study indicate the importance of framing an individual's clinical needs separately in terms of their identity, their beliefs about having mental health problems, needing to see healthcare professionals or needing medication and their view of disabilities. The results also suggest that identity, as measured, was not pivotal to individuals' experiences of living with SEMH problems.

The results highlighted the importance of the social implications of 'overactive behaviour' and work-related experiences which can contribute to an identification as a community member or as a patient. It would appear that socially valued experiences may have contributed to individuals' community identification, through bolstering their self perceptions and other's views taken of them. The results suggested that defensive responses, in the denial or splitting off of the illness from the individual's sense of self, may have been the means by which individuals limited the damaging effects that this could have on their self-worth.

The measure of identity in the current study was suggested as not sufficient to contribute to an understanding of the functional significance of identity in the manifestation of and recovery from SEMH problems. It was proposed that research with a qualitative methodology could aim to capture an understanding of the dynamic nature of the relationship between identity and the severity of problems experienced. Equally, qualitative interviews within a longitudinal study could allow an exploration of the relationship between level of functioning, life events, activities participated in and coping styles that contribute to adapting to living with SEMH problems.

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APPENDICES

- Appendix 1 Ethics consent form**
- Appendix 2 Ethics consent form**
- Appendix 3 Ethics consent form**
- Appendix 4 Ethics consent form**
- Appendix 5 Participant information sheet**
- Appendix 6 Consent form for participants**
- Appendix 7 Consent form for access to medical notes**
- Appendix 8 Interview procedure**
- Appendix 9 Checklist to elicit activities engaged in**
- Appendix 10 Recognition of problems measure**
- Appendix 11 Semantic differential scales (for identity measure)**
- Appendix 12 Awareness of Disabilities Scale**
- Appendix 13 Ladder to rate mental health**
- Appendix 14 Ladder to rate likelihood of keeping job**
- Appendix 15 Ladder to rate likelihood of staying out of hospital**
- Appendix 16 Ladder to rate burden of mental health problems**
- Appendix 17 Rosenberg Self-Esteem Scale**
- Appendix 18 Health of the Nation Outcome Scale**
- Appendix 19 Demographic details checklist**

LREC reference

Ms Jo Macnamara

Dear Ms Macnamara

Re: Identity and response to illness in individuals with severe and enduring mental health problems.

Thank you for meeting with LREC's statistician, on the
I am now able to provide provisional ethical approval for this protocol acting on
Chairman's Action. This decision will be ratified by the full LREC when it meets on the
You should assume that this decision is ratified unless the Committee raise
any further issues in which case I will write again.

Approval is on the understanding that rooms in the clinical setting will be made available for the
interviews and the patient information sheet will be amended to include the investigators
telephone number and the statement 'You do not have to take part in this study and you have the
right to stop the interview at any time' will be in bold typeface.

I would remind investigators that our approval is conditional. Approval may be withdrawn if
the Committee review the study and are concerned about the conduct or consequences of the
work. The Committee require that the investigator inform them of any changes to the
protocol, or any serious adverse events during the work, and expect to be given a copy of the
final research report.

I wish you well in your research endeavours.

Yours, sincerely

Chairman of

Local Research and Ethics Committee

Ms Joanna Macnamara

Dear Ms Macnamara

Protocol: Identity and response to illness in individuals with severe and enduring mental health problems

Our Ref: *(please quote in all correspondence)*

This study has been approved by Chairman's action and further endorsed by another Committee member, under reciprocal arrangements made with Research Ethics Committee.

Yours sincerely

**pp:
Chairman**

Chairman:

Chief Executive

THE

MHS TRUST

Ms J Macnamara
Clinical Psychology Training

Dear Ms Macnamara

**Identity and response to illness in individuals with severe and enduring
mental health problems (- J Macnamara**

Thank you for submitting the above application. This has been approved at the Research Ethics Committee at its meeting on in accordance with the reciprocal arrangement of the Ethics Committees within & Health Authority. However, I would be grateful if you could just confirm that the local consultants whose patients you will be studying have given their approval.

Please note that this project carries a reference number, noted above, which must be quoted in any future correspondence.

The project number and the principal investigator must be clearly stated on the consent form. If approval is given to named investigators only, these names must also be stated on the form.

In the case of research on patients, a copy of the consent form must be placed in the patient's medical records, together with a note of the date of commencement of his/her participation in the research. A label must appear on the outside cover of the records when the patient is participating in the research.

The investigators must adhere to the published Guidelines of the Committee and provide the Chairman with annual progress reports and an end of study report. The research should start within 12 months of the date of approval.

The Hospital LREC is compliant with the requirements.

Yours sincerely

Chairman
Research Ethics Committee

Dear

Re: Identity and Response to illness in individuals with severe and enduring mental health problems ()

Thank you for your letter of undertaking your sponsorship of the above study.

This letter confirms that the study now has full ethical approval.

Please quote Study No. in all future correspondence.

Yours sincerely,

Research Ethics Coordinator

✓ Cc

Information Sheet

Title of study: "Identity and response to mental health problems"

Name of researcher: Jo Macnamara

Introduction

This study is being carried out by Jo Macnamara, Psychologist in Clinical Training, and supervised by _____, a Clinical Psychologist with considerable experience in working with people experiencing mental health problems.

The study

I am interested in how you have made sense of the mental health problems you have and how this affects how you see yourself as a person.

This study will involve answering some questions and should take no longer than about an hour.

The purpose of this research is to look at how you have made sense of your experiences to help me appreciate what is useful in understanding experiences of mental health problems.

What if you refuse to take part or want to stop halfway through ?

If you feel uncomfortable at any time in the study, we can talk about this and also make time at the end of the interview to talk about this further.

You do not have to take part in this study and you have the right to stop the interview at any time. This will in no way affect the service you receive.

Confidentiality

All material will be held in confidence and will be used for research purposes only. Your views will be written up, but no one will be able to tell who was interviewed. However, if there was any serious cause for concern, I would discuss this with you first before talking to your keyworker.

Who should you contact if you have any concerns ?

After the interview if you want any further information you can contact me through your keyworker.

CONSENT FORM FOR PARTICIPATION IN RESEARCH PROJECTS

Title of Project: Identity and response to mental health problems.

Principal Investigator: Joanna Macnamara

Ethics Committee Code No:

Other Investigator/s enrolling patients: Not applicable

Outline Explanation

We would like to invite you to take part in this study. We are interested in how you have made sense of the mental health problems you have and how this effects how you see yourself as a person.

This study will involve answering some questions and should take no longer than 90 minutes.

The purpose of this research is that through paying attention to how you have made sense of your experience, it is hoped that we can gain a better understanding of what is useful in understanding mental health problems.

If you feel uncomfortable at any time in the study, we can talk about this and make time at the end of the interview to talk about this further.

All material will be held in confidence and will be used for research purposes only. Your views will be written up, but no one will be able to tell who was interviewed. However, if there is any serious cause for concern, the investigator would discuss with you their need to mention the issue concerned to your keyworker.

If you refuse to take part halfway through, that is fine because it is your right to do so. Your treatment will not be affected in any way.

I (name) _____

Of (address) _____

Hereby consent to take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I may withdraw from the investigation at any stage without necessarily giving a reason for doing so and that this will in no way affect the care I receive as a patient.

SIGNED

Volunteer _____

Date: _____

Investigator _____

Date: _____

CONSENT FORM FOR ACCESS TO MEDICAL NOTES

Title of Project: Identity and response to mental health problems.

Investigator: Jo Macnamara

Ethics Committee Code No:

I (name) _____

Of (address) _____

Hereby consent to allow Jo Macnamara to have access to my medical notes, so that she is able to gain details on my background history as part of the above study, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction.

SIGNED
Volunteer _____

Date: _____

Investigator _____

Date: _____

Interview Procedure

Each participant will be informed as follows:

I understand that _____, your (CPN / psychiatrist / psychologist) approached you to talk about the study I am carrying out in _____. Here is a copy of the information sheet that he / she would have given you. As you will already know, I am interested in finding out about how having had contact with mental health services has affected how you see yourself as a person. I would be grateful if we could go through some questions and if you could fill in some questionnaires. The whole interview will take about an hour. Your answers will be held in confidence and will be used for research purposes only. Your views will be written up but the results will be written in a general way, so that your answers will not be identifiable. If I am at all concerned about you during the interview, I will talk to you first before speaking with _____, your keyworker /care manager.

If you feel at all uncomfortable during the study, we can talk about this. You do not have to take part in this study and you have the right to stop the interview at any time. This will in no way affect the service you receive.

Are there any questions you would like to ask me about the interview ?

After the interview if you would like further information about the study, you can contact me through your care manager / keyworker.

Following this, the participant will be presented with the consent forms to read and to complete should they wish to continue.

Structured Interview

> “Checklist to elicit activities engaged in ”

I would like to begin by asking you about the activities that you are involved in during a typical week. Take me through from Monday to Friday

Interview procedure continued

> “Recognition of mental health problems”

In your opinion do you believe that you have mental health problems ?

Have you had mental health problems in the past ?

Do you believe that you need to see healthcare professionals ?

Do you believe that you need to take medication for mental health problems ?

> Semantic differential scales (Identity measure)

I would like to look at these scales to rate how you see yourself. For the first scale, “1” represents as relaxed as it is possible to be and “7” represents as tense as it is possible to be, whereas “4” here in the middle represents the point midway between the two. Where do you see yourself on this scale between relaxed and tense ?

(continue throughout scale)

Then repeat though asking participant to rate how they see a typical member of the general public without mental health problems. Next repeat with how they see a typical person who they would view as a “psychiatric patient”.

How have you found the interview so far ? Are there any questions that you would like to ask ?

> Questions from the Awareness of Disabilities Scale (Thompson, 1988)

Here is a ladder to measure how you see your mental health. At the bottom of the ladder “1” represents very unwell, whereas at the top of the ladder “7” represents very well, and “4” is midway between the two. Where on the ladder do you rate your mental health at present ?

Where on the ladder do you think you will be in 3 months time ?

Where on the ladder do you think you will be in one years time ?

Have you thought about taking up a job ? What sort of job ?

Introduce “ladder to rate likelihood”: In terms of how you feel right now, what do you think your chances are of keeping a job? Can you rate this on this new ladder, where “1” is very unlikely and “7” is very likely.

Interview procedure continued

In terms of how you feel right now, what do you think your chances are of staying out of hospital on the same ladder ?

How much would you say that mental health problems are a burden for you ? Introduce third ladder to rate extent of burden of any mental health problems. This time the ladder ranges from "1" which is very low to "7" which is very high.

> Next administer the Rosenberg Self-Esteem Scale.

This is a self-esteem measure. It consists of a list of statements dealing with your general feelings about yourself. Please read each statement and then circle one of these (point) according to how you feel. If you agree circle A. If you strongly agree, circle SA. If you disagree, circle D. If you strongly disagree, circle SD.

End of interview

To end the interview with the following comments:

Thankyou for being so helpful. Some people can find thinking about the issues we have discussed today difficult. Is there anything that we have spoken about today that you would like to discuss further ?

Checklist to elicit activities engaged in

I am interested in the types of activities or interests you tend to be involved in during a typical week.

Take me through the days of the week.

Questions to use as prompts:

Do you attend any of the following ?

Day Centre

social club, eg Drop-In, etc.

other clubs

sports / leisure centre

library

church group

local committee, e.g service user or other

Do you work during the week ? (if so, what it is, hours worked and whether paid)

Are you presently or have you recently completed a course out of interest ?

Are you presently or have you recently completed a vocational course ?

Are you a member of any other clubs or societies ?

Are there any other activities that you get involved in or are planning to start ?

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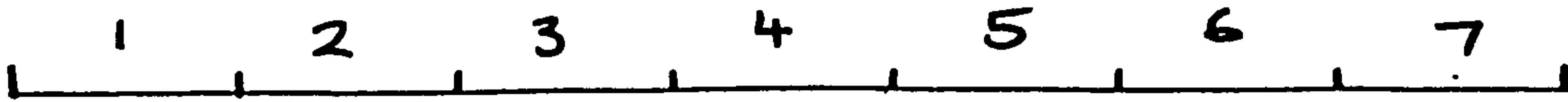
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Recognition of Problems measure

1) Do you believe that you have mental health problems ?

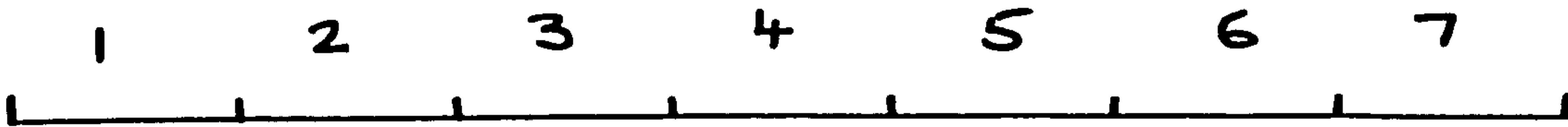
2) Do you believe that you need to see healthcare professionals ?

3) Do you believe that you need to take medication for mental health problems ?



Relaxed

Tense



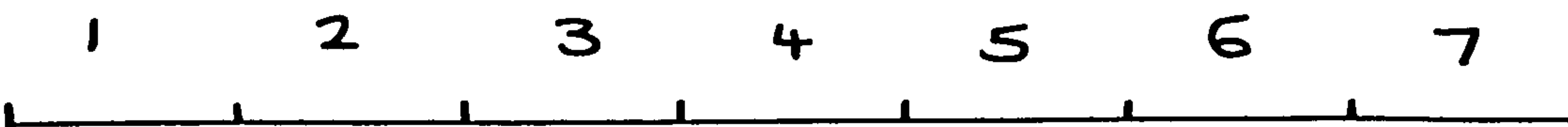
Shy

Outgoing



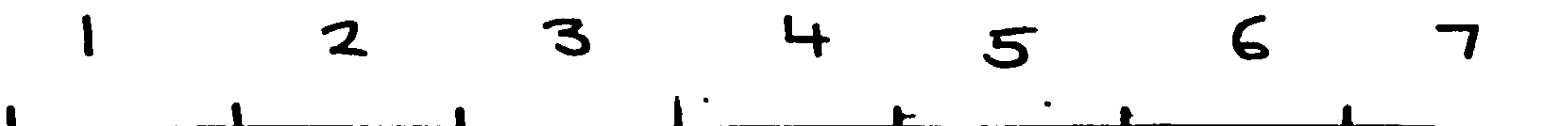
Dependent

Independent



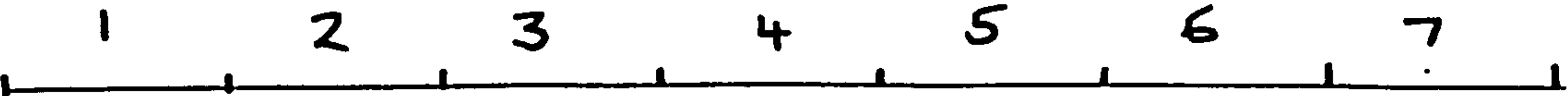
Cooperative

Uncooperative



Withholding

Open with others



Productive

Unproductive



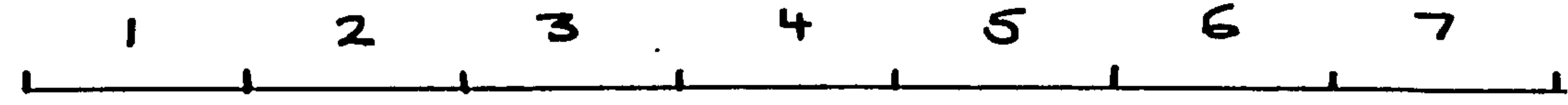
Irritable

Peaceful



Accepted

Rejected



Trapped

Free



Confident

Uncertain



Content

Uneasy



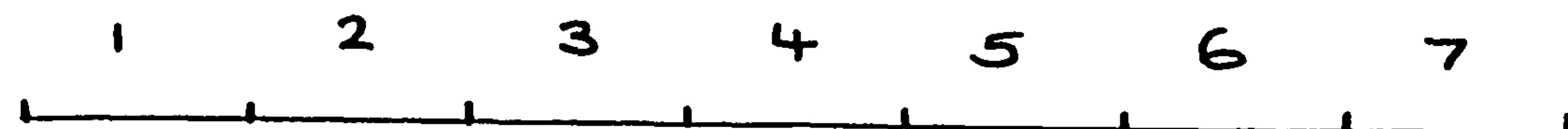
Unfriendly

Friendly



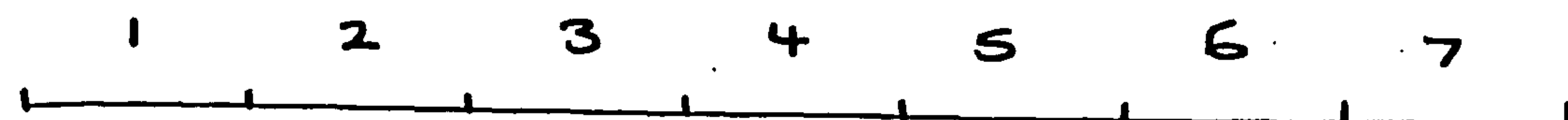
Clear-headed

Confused



Angry

Pleasant



Self-reliant

Reliant on others

1 2 3 4 5 6 7



Tolerant

Intolerant

1 2 3 4 5 6 7



Responsible

Irresponsible

1 2 3 4 5 6 7



Uncomfortable

Comfortable

1 2 3 4 5 6 7



Included

Excluded

1 2 3 4 5 6 7



Gloomy

Cheerful

Questions based on the Awareness of Disabilities Scale (Thompson, 1988)

"Here is a ladder to measure your mental health. Here "1" is very unwell and "7" is very well."

- a) Where on the ladder do you rate your mental health at present ?**

- b) Where on the ladder do you think you will be in 3 months time ?**

- c) Where on the ladder do you think you will be in one years time ?**

- d) Have you thought about taking up a job ? What sort of job ? In terms of how you feel right now, what do you think your chances are of keeping a job? Can you rate this on this new ladder, where "1" is very unlikely and "7" is very likely.**

- e) In terms of how you feel right now, what do you think your chances are of staying out of hospital on this new ladder ?**

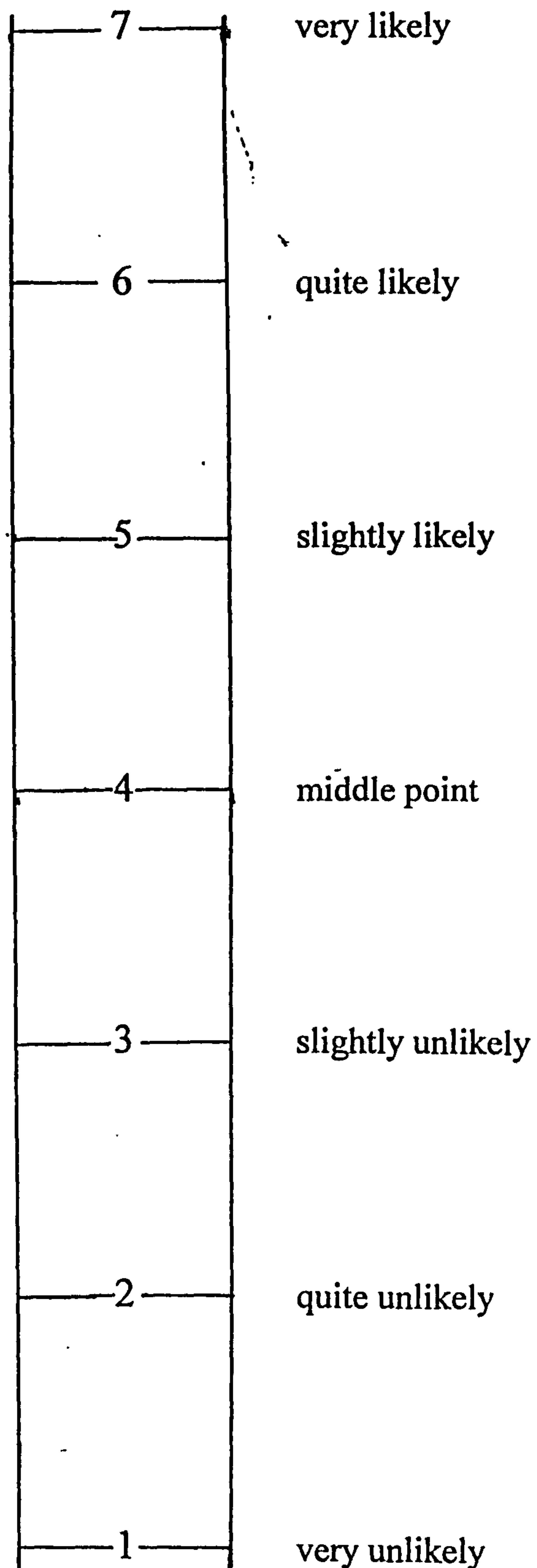
- f) How much would you say that mental health problems are a burden for you ? This time the ladder ranges from "7" which is very high, to "1" which is very low.**

"Ladder to rate mental health"

7	Very well
6	Quite well
5	Slightly well
4	Middle point
3	Slightly unwell
2	Quite unwell
1	Very unwell

“Ladder to rate likelihood of keeping a job”

7	very likely
6	quite likely
5	slightly likely
4	middle point
3	slightly unlikely
2	quite unlikely
1	very unlikely

“Ladder to rate likelihood of staying out of hospital”

"Ladder to rate extent of burden of any mental health problems"

7	Very high
6	Quite high
5	Slightly high
4	Middle point
3	Slightly low
2	Quite low
1	Very low

ROSENBERG SELF-ESTEEM SCALE

APPENDIX 1



Name:

Date: Record Number:

Here is a list of statements dealing with your general feelings about yourself. If you agree with the statement, circle A. If you strongly agree, circle SA. If you disagree, circle D. If you strongly disagree, circle SD. Thank you.

	1 Strongly agree	2 Agree	3 Disagree	4 Strongly disagree
1. On the whole, I am satisfied with myself.	SA	A	D	SD
2. At times I think I am no good at all.	SA	A	D	SD
3. I feel that I have a number of good qualities.	SA	A	D	SD
4. I am able to do things as well as most other people.	SA	A	D	SD
5. I feel I do not have much to be proud of.	SA	A	D	SD
6. I certainly feel useless at times.	SA	A	D	SD
7. I feel that I'm a person of worth, at least on an equal plane with others.	SA	A	D	SD
8. I wish I could have more respect for myself.	SA	A	D	SD
9. All in all, I am inclined to feel that I am a failure.	SA	A	D	SD
10. I take a positive attitude toward myself.	SA	A	D	SD

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**DAMAGED
TEXT
IN
ORIGINAL**

HoNOS

Health of the Nation Outcome Scales



Glossary for HoNOS Score Sheet

HoNOS: August 1995

Authors: J. K. Wing, R. H. Diller, A. S. Beaver
Royal College of Psychiatrists Research Unit,
12th Floor, 12th Avenue, London SW1X 7EE
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Summary of rating instructions:

- 1) Rate each scale in order from 1 to 12
- 2) Do not include information rated in an earlier item except for item 10 which is an overall rating
- 3) Rate the MOST SEVERE problem that occurred during the period rated
- 4) All scales follow the format:
 - 0 = no problem
 - 1 = minor problem requiring no action
 - 2 = mild problem but definitely present
 - 3 = moderately severe problem
 - 4 = severe to very severe problem

Rate 9 if not known

1. Overactive, aggressive, disruptive or agitated behaviour
 - Include such behaviour due to any cause, e.g. drugs, alcohol, dementia, psychosis, depression, etc.
 - Do not include bizarre behaviour rated at Scale 6.
- 0 No problem of this kind during the period rated.
- 1 Irritability, quarrels, restlessness etc. not requiring action.
- 2 Includes aggressive gestures, pushing or pestering others; threats or verbal aggression; lesser damage to property (e.g. broken cup, window); marked overactivity or agitation.
- 3 Physically aggressive to others or animals (short of rating 4); threatening manner; more serious overactivity or destruction of property.
- 4 At least one serious physical attack on others or on animals; destructive of property (e.g. fire-setting); serious intimidation or obscene behaviour

Rate 9 if not known

2. Non-accidental self-injury

- Do not include accidental self-injury (due e.g. to dementia or severe learning disability); the cognitive problem is rated at Scale 4 and the injury at Scale 5.
 - Do not include illness or injury as a direct consequence of drug/alcohol use rated at Scale 3 (e.g. cirrhosis of the liver or injury resulting from drink driving are rated at Scale 5).
- 0 No problem of this kind during the period rated.
 - 1 Fleeting thoughts about ending it all but little risk during the period rated; no self-harm.
 - 2 Mild risk during the period rated; includes non-hazardous self-harm (e.g. wrist-scratching).
 - 3 Moderate to serious risk of deliberate self-harm during the period rated; includes preparatory acts (e.g. collecting tablets).
 - 4 Serious suicidal attempt and/or serious deliberate self-injury during the period rated.

Rate 9 if not known

3. Problem-drinking or drug-taking

- Do not include aggressive/destructive behaviour due to alcohol or drug use, rated at Scale 1.
 - Do not include physical illness or disability due to alcohol or drug use, rated at Scale 5.
- 0 No problem of this kind during the period rated.
 - 1 Some over-indulgence but within social norm.
 - 2 Loss of control of drinking or drug-taking, but not seriously addicted.
 - 3 Marked craving or dependence on alcohol or drugs with frequent loss of control, risk taking under the influence.
 - 4 Incapacitated by alcohol/drug problem.

Rate 9 if Not Known

Rate 9 if Not Known

4. Cognitive problems

- Include problems of memory, orientation and understanding associated with any disorder: learning disability, dementia, schizophrenia, etc.
- Do not include temporary problems (e.g. hangovers) resulting from drug/alcohol use, rated at Scale 3.

- 0 No problem of this kind during the period rated.
- 1 Minor problems with memory or understanding (e.g. forgets names occasionally).
- 2 Mild but definite problems (e.g. has lost the way in a familiar place or failed to recognise a familiar person); sometimes mixed up about simple decisions.
- 3 Marked disorientation in time, place or person; bewildered by everyday events; speech is sometimes incoherent; mental slowing.
- 4 Severe disorientation (e.g. unable to recognise relatives), at risk of accidents; speech incomprehensible; clouding or stupor.

6. Problems associated with hallucinations and delusions

- Include hallucinations and delusions irrespective of diagnosis.
- Include odd and bizarre behaviour associated with hallucinations or delusions.
- Do not include aggressive, destructive or overactive behaviours attributed to hallucinations or delusions, rated at Scale 1.

- 0 No evidence of hallucinations or delusions during the period rated.
- 1 Somewhat odd or eccentric beliefs not in keeping with cultural norms.
- 2 Delusions or hallucinations (e.g. voices, visions) are present, but there is little distress to patient or manifestation in bizarre behaviour, i.e. clinically present but mild.
- 3 Marked preoccupation with delusions or hallucinations, causing much distress and/or manifested in obviously bizarre behaviour, i.e. moderately severe clinical problem.
- 4 Mental state and behaviour is seriously and adversely affected by delusions or hallucinations, with severe impact on patient.

Rate 9 if Not Known

5. Physical illness or disability problems

- Include illness or disability from any cause that limits or prevents movement, or impairs sight or hearing, or otherwise interferes with personal functioning.
- Include side-effects from medication; effects of drug/alcohol use; physical disabilities resulting from accidents or self-harm associated with cognitive problems, drink-driving, etc.
- Do not include mental or behavioural problems rated at Scale 4.

- 0 No physical health problem during the period rated.
- 1 Minor health problems during the period (e.g. cold, non-serious fall, etc.).
- 2 Physical health problem imposes mild restriction on mobility and activity.
- 3 Moderate degree of restriction on activity due to physical health problem.
- 4 Severe or complete incapacity due to physical health problem.

Rate 9 if Not Known

7. Problems with depressed mood

- Do not include overactivity or agitation, rated at Scale 1.
- Do not include suicidal ideation or attempts, rated at Scale 2.
- Do not include delusions or hallucinations, rated at Scale 6.

- 0 No problem associated with depressed mood during the period rated.
- 1 Gloomy; or minor changes in mood.
- 2 Mild but definite depression and distress (e.g. feelings of guilt; loss of self-esteem).
- 3 Depression with inappropriate self-blame, preoccupied with feelings of guilt.
- 4 Severe or very severe depression, with guilt or self-accusation.

Rate 9 if Not Known

8. Other mental and behavioural problems

- Rate only the most severe clinical problem not considered at items 6 and 7 as follows.
- Specify the type of problem by the entering the appropriate letter:
A phobic; B anxiety; C obsessive-compulsive;
D mental strain/tension; E dissociative; F somatoform.
G eating; H sleep; I sexual; J other, specify.

- 0 No evidence of any of these problems during period rated.
- 1 Minor non-clinical problems.
- 2 A problem is clinically present at a mild level (e.g. patient has a degree of control).
- 3 Occasional severe attack or distress, with loss of control (e.g. has to avoid anxiety provoking situations altogether, call in a neighbour to help, etc.) i.e. moderately severe level of problem.
- 4 Severe problem dominates most activities.

Rate 9 if Not Known

9. Problems with relationships

- Rate the patient's most severe problem associated with active or passive withdrawal from social relationships, and/or non-supportive, destructive or self-damaging relationships.

- 0 No significant problems during the period.
- 1 Minor non-clinical problems.
- 2 Definite problems in making or sustaining supportive relationships: patient complains and/or problems are evident to others.
- 3 Persisting major problems due to active or passive withdrawal from social relationships and/or to relationships that provide little or no comfort or support.
- 4 Severe and distressing social isolation due to inability to communicate socially and/or withdrawal from social relationships.

Rate 9 if Not Known

10. Problems with activities of daily living

- Rate the overall level of functioning in activities of daily living (ADL): e.g. problems with basic activities of self-care such as eating, washing, dressing, toilet; also complex skills such as budgeting, organising where to live, occupation and recreation, mobility and use of transport, shopping, self-development, etc.)
- Include any lack of motivation for using self-help opportunities, since this contributes to a lower overall level of functioning.

- Do not include lack of opportunities for exercising intact abilities and skills, rated at Scales 11-12.

- 0 No problems during period rated; good ability to function in all areas.
- 1 Minor problems only (e.g. untidy, disorganised).
- 2 Self-care adequate, but major lack of performance of one or more complex skills (see above).
- 3 Major problems in one or more area of self-care (eating, washing, dressing, toilet) as well as major inability to perform several complex skills.
- 4 Severe disability or incapacity in all or nearly all areas of self-care and complex skills.

Rate 9 if Not Known

11. Problems with living conditions

- Rate the overall severity of problems with the quality of living conditions and daily domestic routine. Are the basic necessities met (heat, light, hygiene)? If so, is there help to cope with disabilities and a choice of opportunities to use skills and develop new ones?
- Do not rate the level of functional disability itself, rated at Scale 10.

NB: Rate patient's usual accommodation. If in acute ward, rate the home accommodation. If information not available, rate 9.

- 0 Accommodation and living conditions are acceptable; helpful in keeping any disability rated at Scale 10 to the lowest level possible, and supportive of self-help.
- 1 Accommodation is reasonably acceptable although there are minor or transient problems (e.g. not ideal location, not preferred option, doesn't like the food, etc.)
- 2 Significant problem with one or more aspects of the accommodation and/or regime (e.g. restricted choice; staff or household have little understanding of how to limit disability, or how to help use or develop new or intact skills).
- 3 Distressing multiple problems with accommodation (e.g. some basic necessities absent); housing environment has minimal or no facilities to improve patient's independence.
- 4 Accommodation is unacceptable (e.g. lack of basic necessities; patient is at risk of eviction or 'roofless'; or living conditions are otherwise intolerable) making patient's problems worse.

12. Problems with occupation and activities

- Rate the overall level of problems with quality of day-time environment. Is there help to cope with disabilities, and opportunities for maintaining or improving occupational and recreational skills and activities? Consider factors such as stigma, lack of qualified staff, access to supportive facilities, e.g. staffing and equipment of day centres, workshops, social clubs, etc.
 - Do not rate the level of functional disability itself, rated at Scale 10.
- NB: Rate patient's usual situation. If in acute ward, rate activities during period before admission. If information not available, rate 9.**

- 0 Patient's day-time environment is acceptable: helpful in keeping any disability rated at Scale 10 to the lowest level possible, and supportive of self-help.
- 1 Minor or temporary problems (e.g. late giro cheques; reasonable facilities available but not always at desired times, etc.).
- 2 Limited choice of activities, e.g. there is a lack of reasonable tolerance (e.g. unfairly refused entry to public library or baths etc.); or handicapped by lack of a permanent address; or insufficient carer or professional support; or helpful day setting available but for very limited hours.
- 3 Marked deficiency in skilled services available to help minimise level of disability; no opportunities to use intact skills or add new ones; unskilled care difficult to access.
- 4 Lack of any opportunity for daytime activities makes patient's problems worse.

HONOS Score Sheet**Scale 0-4****Rate 9 if not known**

1 Overactive, aggressive, disruptive or agitated behaviour	<input type="checkbox"/>	<input type="checkbox"/>
2 Non-accidental self-harm	<input type="checkbox"/>	<input type="checkbox"/>
3 Problem-drinking or drug-taking	<input type="checkbox"/>	<input type="checkbox"/>
4 Cognitive problems	<input type="checkbox"/>	<input type="checkbox"/>
5 Physical illness or disability problems	<input type="checkbox"/>	<input type="checkbox"/>
6 Problems with hallucinations & delusions	<input type="checkbox"/>	<input type="checkbox"/>
7 Problems with depressed mood	<input type="checkbox"/>	<input type="checkbox"/>
8 Other mental & behavioural problems (specify A, B, C, D, E, F, G, H, I or J)	<input type="checkbox"/>	<input type="checkbox"/>
9 Problems with relationships	<input type="checkbox"/>	<input type="checkbox"/>
10 Problems with activities of daily living	<input type="checkbox"/>	<input type="checkbox"/>
11 Problems with living conditions	<input type="checkbox"/>	<input type="checkbox"/>
12 Problems with occupation and activities	<input type="checkbox"/>	<input type="checkbox"/>
Total Score (0-48)	<input type="checkbox"/>	<input type="checkbox"/>

Demographic details checklist

- Age
- Ethnicity
- Diagnosis
- Length of contact with psychiatric services
- Time spent in hospital
- Whether taking medication currently
- Length of employment (pre and post first becoming unwell)
- Qualifications
- Accommodation type
- Current significant relationship